

**RESEARCH PROJECT**

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**M MED FAMILY MEDICINE**

**RICHARD COOKE**

**STUDENT NUMBER: 13019163**

**CONTACT MOBILE: 0842403857**

**CONTACT EMAIL: richacooke@yahoo.com**

**SUPERVISOR DR HOFFIE CONRADIE**

**CONTACT NUMBER: 0828557568**

**LAYING THE FOUNDATIONS TO RESTRUCTURE THE  
MADWALENI HIV WELLNESS PROGRAMME, USING  
KNOWLEDGE OF THE COMMUNITY PERCEPTIONS OF  
THE PROGRAMME, IN RELATION TO THE NEEDS AND  
PRIORITIES WHILE LIVING WITH HIV.**

## **ABSTRACT**

Madwaleni Hospital is situated in a deeply rural area of the Eastern Cape Province of South Africa, serving a catchment population of approximately 262,300 within a 35 kilometer radius.

An HIV programme was started in mid-2005 to try and address some of the HIV burden faced by the community. The pillars to the Madwaleni HIV programme comprise VCT (voluntary counselling and testing) and the HIV Wellness programme – a group of family-oriented services (including provision of antiretrovirals) offered to HIV positive individuals within the framework of local support groups meeting at the local hospital, community health center and primary health clinics. As at end August 2009, there are 3760 Wellness programmes members, of whom 1700 are on antiretrovirals.

## **RESEARCH AIM**

The purpose of this research was to obtain an in-depth understanding of individual's perception of the success of the Madwaleni HIV Wellness Programme in the context of the individual needs in living with HIV.

## **RESEARCH OBJECTIVES**

The objectives were as follows:

- To determine the factors influencing HIV positive individuals to join or not join the Madwaleni HIV Wellness programme.
- To assess the community understanding of the programme in the context of the community lived in, including the perceived priority health and social problems in the Madwaleni/Mbashe community.
- To recommend modifications to the existing HIV programme outcomes by which the success of the Madwaleni HIV programme is determined, in light of the information gained by the first two objectives listed above.

## **LITERATURE REVIEW**

Many of the studies evaluating the efficacy of wellness or support programmes have focused on support for cancer patients, with an occasional review of other chronic disease programmes. For HIV+ patient support groups, the literature focuses on arguments for their existence in the context of a theoretical model, and evaluations highlighting the differences/similarities between the groups. Where quantitative analyses have been conducted, the traditional support group providing inter-personal support is significantly beneficial only if led by a trained facilitator. In addition, groups that are led and structured to provide psycho-educational support are superior to the social groups relying on inter-member support alone.

There is little evidence in the literature of objective, scientific evaluation of the benefit of HIV support programmes. There is often a lack of scientific theoretical basis for the support group interventions. By far the most studies are set in the developed world. Owing to the demographics of the HIV population in the first world, most support programmes focus on men, and/or gay men and women in particular. There are many studies focusing on rural support programmes, but the relevance remains limited since they are based predominantly in the United States. The rural setting of HIV in South Africa offers a unique set of challenges, and the attitudes of rural South Africans are neatly outlined in some local studies

## **METHODOLOGY**

The qualitative study design used open-ended questions in a number of focus groups of study participants, including an initial pilot. Individual interviews were held with participants where stigma concerns and/or non-membership of the HIV programme precluded participation in a focus group:

- GROUP A      Madwaleni HIV staff members (HIV positive members) and support group members
- GROUP B      HIV support group members at Xora Community Health Center
- GROUP C      HIV positive members not joining the programme (and not on ARVs)
- GROUP D      HIV programme members who are infrequent attendees.
- GROUP E      Community Leaders (Chiefs)

## **RESULTS**

### **GROUPS A and B:      MEMBER EXPECTATIONS AND CONCERNS THAT HELP/HINDER PEOPLE JOINING AND ATTENDING**

In the minds of the HIV programme management and staff, the current expectation of persons who test positive for HIV is that each needs to undergo a psychological self-acceptance of their positive status before – and even in order to – join the programme through attendance of a support group. This research shows that this acceptance is in fact a process for many; Part of the process is joining the support group, but the drivers towards joining are the awareness created during the initial voluntary counselling and testing (fairly weak) and the knowledge of antiretrovirals (very strong) rather than the status acceptance. A psyche of denial even exists among some support group members when they first join.

The research confirms that there are many geographical factors which are a hindrance to joining the programme. Poor public transport and lack of money are expected problems, but the access problems are present for members attending the primary health clinics as well as the hospital, despite the efforts to solve the problem of access to the latter by decentralization of the programme to clinic level.

Mutual support is very strong within the support group structures in so far as the positive effects of internal knowledge and bonding impact repeat attendance, but that impact on external (non-members) motivation to join is obviously indirect and therefore limited. In addition, members highlight the support gap between the initial counselling at the point of testing and that available within the support groups. The findings (including in Groups C and D) confirm the former is less effective for the limitations of providing detailed plans and support in the immediacy of a positive HIV test. Furthermore, the latter in-house programme support tends towards didactic, authoritarian instruction by established peer educators, rather than a facilitative, listening-based approach. The group interaction is seen as more beneficial than the individual counselling given by HIV positive non-professionals. Whether individually successful or not, the components of support are provided in the context of the programme itself – negative community perceptions around HIV are, accordingly, not targeted directly. These perceptions remain, on balance, non-conducive to people joining and attending the programme.

The findings necessitated highlighting a form of bonding that is centered on dependencies of the support group members. The impact of an impoverished lifestyle means there is a constant insecurity around access to basic needs. This fuels a mentality that is termed “hand-to-mouth” in this research, which is a platform for material expectations in being a member of the HIV programme. This dependency has a significant association (positive) with mutual support amongst members, but concurrently dilutes the group focus on individual acceptance of an HIV positive status. Be that as it may, such a dependency does have a positive effect on individuals joining and attending the HIV programme.

In recognizing the importance of an understanding of the course of HIV-associated disease in the context of managing its chronic, most-often insidiously progressing nature, the results disappointingly reflected a residual focus on reacting to illness, rather than a proactive understanding of “HIV Wellness”, despite education encouraging the latter. As a general rule concerning individuals living with HIV, this limited understanding does not increase motivation to join the programme early in the course of his/her disease.

Within the family unit, there are many issues that are hindrances to a person joining and attending the HIV programme. Marriage itself has a mixed impact - a negative association for females, but positive for males), but it is the issue of paternal dominance that tarnishes potential of the family unit to be a platform from which joining the programme is encouraged. .

In the minds of members, the presence of antiretrovirals is very strong, closely coupled with its sub-theme of adherence to medication. Together they are key drivers for both joining and subsequent attendance.

Knowledge and understanding of the HIV virus itself was also raised in the focus groups. Coupled with an apparent mediocre understanding of “HIV Wellness” and the course of disease, there is a similar confusion between the HIV virus and the clinical syndrome of AIDS. Any understanding around the virus itself is a help to people deciding to join and attend the programme only in so far as viral control by ARVs (a dominant theme) improves people’s motivation.

For not being raised significantly as a theme in the focus groups, there is no clear evidence that choice of lifestyle is a help or hindrance overall to numbers joining and attending the programme.

**GROUPS A and B:      SYSTEM ISSUES HELPING/HINDERING PEOPLE TO  
JOIN AND ATTEND**

The themes identified in the focus groups A and B were distinguished for the factors affecting the members for their environment and circumstances, as opposed to the system elements of the programme itself. The latter concepts raised in the focus groups include the practice of following-up of members in the community by counselors, often through home visits, the idea (not currently in place) of splitting the support group into different groups, the clinical support offered by the health professionals, staff confidentiality, counselling, the concept of a one-stop-shop of HIV services and the practical issues of the waiting times and queues facing members on attendance for the various services. Excessive waiting times and queues, in particular, emerged as key hindrances to ongoing attendance.

The subject of clinical support is not raised frequently at all as an appreciated service, and there are few quotes relating to the specific assistance provided by either nurses or doctors. This form of support is however associated with such concepts as illness and health (as member-centered needs, which collectively account for a significant proportion of the discussion. This suggests the need is recognized but the service itself is either under-appreciated or seen (correctly) as a patient right for which little acknowledgement is required.

To the extent that a one-stop-shop (accessing different HIV Wellness services during one visit) may help encourage joining and attending, it is not a well-established concept, suggesting this factor does not contribute a measure of success in general member-evaluation of the programme systems in place.

Member follow-up is acknowledged as being related to adherence problems: members who do not collect their ARVs are proactively sought, rather than following up those who do not attend support group.

The stigma attached to the white car – an HIV programme car known to the community – undermines the supportive intention of the staff in conducting a home visit. On balance, however, the home visit is perceived as a useful and appreciated service by members.

Participants felt there could be advantages to a split support group; the distinction in groups to be made around issues of adherence to ARVs as well as the length of time on ARVs.

Staff confidentiality was a poorly-established concept, possibly for reasons none of the focus group participants were health care workers.

Counselling - with respect to the individual support given by lay counsellors, nurses or doctors - is a poorly-established concept, as opposed to the informal counselling between members themselves, well-established as the theme of mutual support.

#### **GROUPS C and D: REASONS WHY PEOPLE DO NOT JOIN AT ALL, OR ATTEND INFREQUENTLY**

In addition to the same problems with transport and lack of money already identified, logistics hindering unencumbered joining and attending include the fact that travelling to hospital and clinic can be restricted to days soon after the monthly date of grant payment, as well as individuals finding attendance time-consuming irrespective of how busy they are.

Incorrect and/or misinterpretation of education and counselling messages contribute significantly to the growth of misconceptions that adversely affect joining and attendance. The two culprits contributing to these misconceptions are the need to standardize education messages and the need for task shifting from health professional to lay counsellor in the face of scarcity of the former.

The frequency (and ease with which) the rationale of not being either ready or ill (especially the former) was used to explain why programme membership has been delayed is significant. The two excuses of “not ready” and “not ill” help perpetuate specific denialism, which grossly hinders people’s likelihood of joining the programme.

Access problems are complicated by a migrant component to the local community. Temporarily living in the Mbashe sub-district, as well as living far from Mbashe - hinder individuals from being able to join the programme. The associated high prevalence of fractured families is a key reason why the family unit does not, on balance, provide a supportive environment in helping individuals join and attend.

Individuals who are wary of ARVs provided reasoning related to the difficulties with taking concurrent medication, the prevalence of side-effects, and a high pill burden.

The issues related to the understanding of the course of disease and status acceptance were both similar to the associations established in focus groups A and B.

#### **GROUP E      COMMUNITY LEADERS IMPRESSION OF THE HIV PROGRAMME AND WHY PEOPLE JOIN AND ATTEND**

In witnessing the success of the programme, the chiefs are motivated to improve on partnering the programme, a key theme that was present in this focus group. Contradictions are evident in the transcripts, notably between their respect for autonomy of the members/patients and the autocratic leadership style displayed. The transcripts acknowledge the practice of canvassing the community to gauge community perceptions around the issues of HIV in general. When members are defaulting attendance and ARVs, however, the emphasis around the role of the chiefs shifts from one of consulting to one of giving direction to community members in what is perceived to be their best interests. In the interests of partnering the programme to persuade people to join (or defaulters to follow-up) therefore, the transcripts revealed a propensity on the part of the chiefs to err on the side of an autocratic approach.

A respect for HCWs (health care workers) lessens the autocratic leadership style, and when raised, a compromise is evident: neither the authority of the community leaders nor the autonomy or self-determination of the individual is threatened.

Despite the programme being government run, government- in the broader sense - is seen as being responsible for perpetuating some of the stigma and non-disclosure associated with HIV, by concentrating over-cautiously on confidentiality and recognition of autonomy. On balance the patient rights relating to confidentiality and recognising autonomy are seen by the chiefs as conflicting with the objective of increased membership.

Transport and logistics are also recognised as a hindrances to joining and attending by the chiefs as by other focus group participants, but the chiefs nevertheless have an impression that the reach of the programme, and the number of people on the programme , are both more than is actually the case. Their optimism however, does not extend to the problems around the community perceptions; their understanding is in keeping with that of the other focus groups. The exception relates to their understanding of the impact of the family unit: while their understanding of its importance is the same as the community, the chiefs considers the family unit as more of a help to joining and attending than is reflected in the other focus groups. Their definition of mutual support includes elements outside the programme, and so is this mutual support is seen as more of a help to joining and attending than that concluded from focus groups A-D.

Lifestyle choices are seen as more of a hindrance to joining and attending on a community level, as opposed to a neutral association in the other focus groups. Fuelling this belief is a more prominent



place of the concept of HIV Wellness (as opposed to reacting to illness) in the understanding and comments of the chiefs than that of the community, whether members or non-members.

## RECOMMENDATIONS

The following recommendations are made in light of the above findings:

1. Targeting specific problems concerning access to care and stigma.
2. Debate the merits of the voluntary counselling and testing (VCT) in its current form, with six-monthly auditing of the standard of counselling, the close monitoring of the numbers tested, and the possible introduction of a pamphlet to issue both those testing positive and negative with follow-up information included.
3. Improve the recording of all those tested HIV positive at VCT stations for future confidential follow-up.
4. Proactive identification of vulnerable children of adults attending VCT stations in the hospital and community
5. Withdrawal of mandatory support group membership as criteria for access to the HIV programme
6. Streamlining the support group to focus primarily on new attendees needing help with self-acceptance of their HIV positive status
7. Introducing health programmes and income generation projects (run and organised by volunteers and staff members) doubling as HIV support forums for the “veteran” HIV positive individuals
8. Using the HIV support group – training group system as a two-way feeder system. Trainees testing positive for HIV will be referred out to a HIV support group for newly diagnosed HIV positive individuals. HIV positive individuals who have spent the minimum time learning in the support group can be referred to training/income generation programmes
9. Integrating the HIV clinic into outpatients clinic, starting with referral of those on antiretrovirals for more than a year for pill collection and clinical review in general outpatients department.
10. Development of pharmacy assistants as HIV counsellors as they are currently underutilised
11. Establish traditional leaders’ forums for regular liaison on possible programme improvements, as well as collective marketing of HIV- and programme-related information outside of the programme. Stakeholders will include sub-district management staff, and clinic staff.
12. Establish traditional healers’ forums in which to explore partnerships between service providers in the interests of marketing information on HIV wellness, concurrent diseases and the support available.
13. Establish formal referral systems between the main employers in Gauteng and the HIV Wellness programmes in the Madwaleni-Mbashe area (predominantly mining companies) to target the problems of fractured families. This must then evolve to collectively strategizing on

a way forward in proactively minimising the health impacts of the migrant labour system on the families in the Madwaleni-Mbashe region.

14. Incidental modifications of form to include more counselling tools to promote status acceptance and motivational interviewing.
15. The scope of a specific strategy to redefine dependency on mutual support and HIV Wellness rather than finding the money to survive is obviously limited within a small health programme. Education on the financial management of pension, grant and other income is one practical intervention, perhaps offered within the setting of an income-generation group. While the reliance on grant money has to be tackled, the inconsistencies of application of eligibility criteria by health professionals must be addressed. Likewise, the deficiencies of the local Department of Social Development must be exposed for their reluctance to partner the local Department of Health structures in helping those eligible for social welfare assistance.
16. This research highlights the need to capacitate this programme with support group facilitators. A debate is needed on whether lay counselors can be trained in such skills (and if so, to what degree), given the scarcity of trained professionals who would ideally be used. The misconceptions raised in focus groups C and D suggest a further debate is required as to whether to the practicality of having individual counselors develop topic-specific expertise (to have some champions of counselling on prevention of mother-to-child transmission and others on HIV/TB, for example). More creative use of stipended payments to volunteers can assist in this process.
17. Support for HIV programme staff (themselves members) to include individual debriefing and counselling sessions, as well as mandatory clinical reviews
18. Addition of more measurable standards relating to monitoring of the process leading to the clinical outcomes, such as auditing of waiting times, standards of VCT, standards of counselling, and percentage joining the programme who test HIV positive over a defined period of time.

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## INTRODUCTION

Since the 1990s, multiple advances in HIV treatment have resulted in improvements in health outcomes for HIV positive persons worldwide. Outcomes have included reduction in morbidity and mortality and the reduction in transmission of the virus – notably for those HIV positive persons adhering to their regimens of antiretrovirals (ARVs). Due to treatment advances by 2003, studies have projected a per-person survival increase of 13.3 years in treated vs. untreated individuals. The introduction of antiretrovirals has, however, not resulted in the conquering or even controlling of the HIV pandemic. Worldwide there are currently an estimated 44 million people who are HIV positive, of whom 5.5 million live in South Africa. 1000 people die of AIDS in South Africa every day (Walesky et al, 2006).

The rural people of South Africa however, remain the most marginalized group in the country. Poor access to health care, high unemployment and a poor average skill set are common problems experienced by thousands of people. Although antiretrovirals currently receive most of the attention from all sides in the health debate, other “HIV Wellness” initiatives aimed at improving the lives of HIV positive individuals overall are important to maintain health and delay the necessity of ARVs.

Madwaleni Hospital is situated in a deeply rural area of the Eastern Cape Province of South Africa, serving a catchment population of approximately 262,300 within a 35 kilometer radius. (District Health Information System, 2008).



Figure 1: Map of South Africa, indicating the Eastern Cape and Mthatha (2007)

(<http://www.geology.com> 2008)

Madwaleni Hospital, as well as the six attached Primary Health Clinics (PHCs) of Bomvana, Melitafa, Mqhele, Nkanya, Hobeni and Soga and the attached Community Health Centre (CHC) Xora belong to the Mbashe Municipality, the fifth most socio-economically deprived municipality in the country. ((District Health Information System, 2008).



Built by the Dutch Reformed Missionaries in 1959, Madwaleni Hospital was then taken over by the Department of Health (DoH) of the South African government in 1976. It is a primary level hospital with 200 operational beds distributed between its seven wards: Maternity, Paediatrics, Female General, Male General, Isolation, TB Female and TB Male. In the Out-patients Department (OPD) between 70 and 120 out-patients are seen every day. This department, which includes the rehabilitation department and pharmacy, forms the main backdrop to the patient-provided interaction at the hospital. Since the laboratory, X-ray facility and small operating theatre have limited facilities, patients are referred to NMAH for all specialists' consultations and surgery, except for minor

operations and caesarean sections. Outpatient programmes attached to the hospital are an HIV/ARV programme, a Home-based Care (HBC) programme and an Orphans and Vulnerable Children (OVC) programme.

From a usual number of four doctors in the earlier years of this decade, Madwaleni Hospital now has a total of nine doctors and six allied health professionals. The latter group consists of one pharmacist, two physiotherapists, two occupational therapists, and one HIV site coordinator. Only one doctor, the pharmacist and the social worker are members of the Xhosa community themselves, while the other twelve health care professionals are foreigners in this community. In addition, 123 nurses are employed by the hospital, of whom 67 are junior nurses with respectively one or two years of training and 56 are professional nurses with full three years of training. The nurses are mostly Xhosa-speaking, but 2008/9 has seen an influx of Zulu nurses from the neighbouring province KwaZulu Natal.

#### THE MADWALENI HIV WELLNESS PROGRAMME

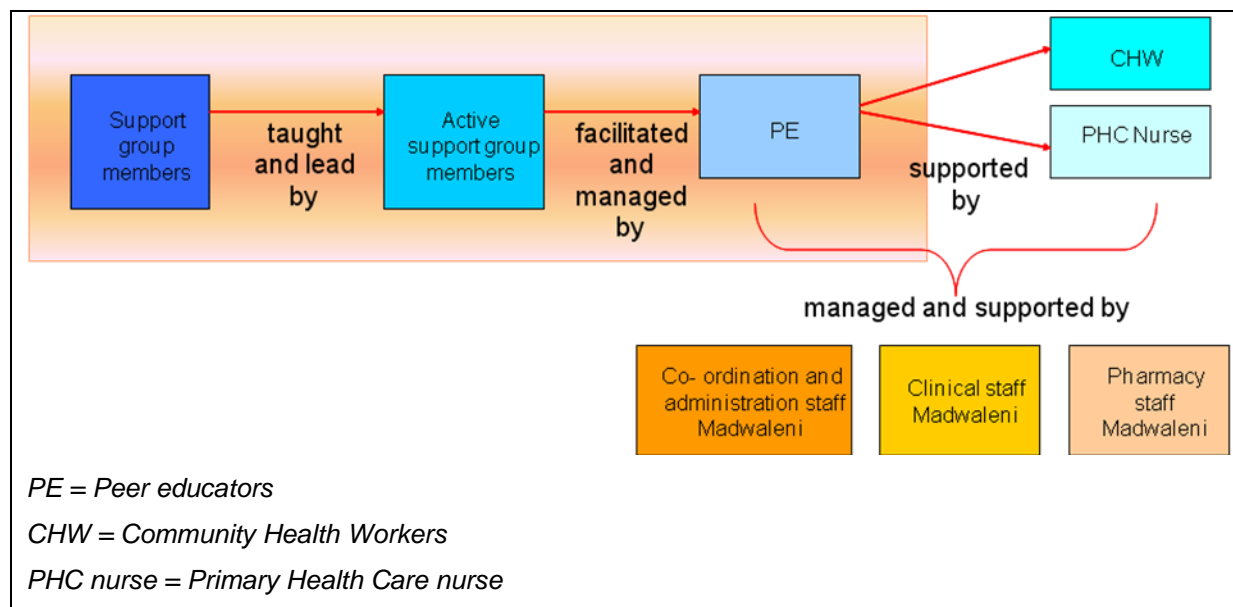
An HIV programme was started in mid-2005 to try and address some of the HIV burden faced by the community. The pillars to the Madwaleni HIV programme comprise VCT (voluntary counseling and testing) and the HIV Wellness programme – one aspect of which is an antiretroviral (ARV) programme itself. HIV support groups form the backbone of the programme. Adults, children, and pregnant women are catered for to varying degrees. The programme is decentralized - there are 26 clinics in the sub- district – the programme is run at seven of these. These clinics are linked to one of three community health centers (CHCs) in the Mbashe sub-district, namely Xora. The Madwaleni team of health professionals “supports the support groups” through capacitating a group of counselors who run the support groups, and clinic visits once or twice a month. 18 counselors are part of the team, of whom 14 are lay peer educators who are fulltime employed HIV+ members of the programme themselves and four are community health workers. As at August 2009, there are 3760 HIV Wellness Programme members of whom 1700 are on antiretroviral treatment.

The Madwaleni HIV Wellness Programme comprises a group of family-oriented services offered to HIV positive individuals within the framework of local support groups meeting at the local hospital, community health center and primary health clinics. These services include:

Membership of a local HIV support group
Education and health advice
Ongoing counseling on living with HIV
Home visits
Counseling on readiness for ARVs
Nutrition advice
Provision of all services at local clinic level

Family planning, screening for cervical cancer, contraception and couple counseling
PMTCT (Prevention of mother to child transmission) and infant follow-up clinics
Regular screening and treatment of opportunistic infections
Assessment for social grants

**Table 1: Services provided in the Madwaleni HIV Wellness Programme**



**Figure 3: Support groups and task shifting in the Madwaleni HIV Wellness Programme**

Each wellness patient has a personal HIV wellness file – opened at the third support group visit (Appendix 1) when joining the programme. A specific form is completed to screen patients when opening a file (demographics) and then subsequent “visits” completed when the patient attends the 2-weekly counseling sessions on their respective support group days (HIV Wellness and readiness criteria for ARVs, appendix 2). The information requested from the patient is standardised since there are different staff members who will see the patient, including community health, nurses and doctors at the hospital and at each clinic (where the system is duplicated). At the outset, the rationale for standardising the forms – rightly or wrongly – was to provide a framework for less skilled, more isolated health practitioners to actively manage patients.

A comprehensive data system is in place, with user-friendly forms for completion by the clinicians. The specific outcome standards currently focus on CD4 (growth in immune system defenses) and viral load data (adequate and prolonged suppression).

Between July 2005 and December 2008, 1343 adults were commenced on ART at Madwaleni, of which 204 started as inpatients. Baseline characteristics were median CD4 count 117 (IQR 50 to 184), age 32 years (IQR 27 to 39). Median duration on ART was 9.8 months (IQR 4.3 to 20.2). Virological suppression (<400 copies/mL) were 87%, 87% and 88% respectively for years 1, 2 and 3. Overall loss to follow-up rate was 3.7% and death rate was 10.6% (Leisengeng R. et al., 2009).

## MOTIVATION FOR CONDUCTING THIS RESEARCH

Madwaleni serves a catchment population of approximately 130 000. VCT statistics indicate an HIV prevalence of 17% - equaling approx 22 000 HIV+ individuals. With 3760 members as at the end of August 2009, the programme is now well-established but falls well-short of claiming good coverage in the sub-district with respect to numbers accessing the programme. Notwithstanding any success, the programme needs to evolve. Membership has grown, but the novelty has worn off and “ARV veterans” are reluctant to remain involved. The programme staff has identified problems; most notably the low conversion rate from testing positive at VCT to joining the Wellness programme. In 2009, for the months to May, of the persons testing HIV positive, only 30% joined the HIV programme (Madwaleni Programme database, 2009).

The independent research company Aurum Institute of Health and Research and the Donald Woods Foundation are now funding partners, who are both supportive rather than directive of this government programme. The time is right to look critically at aspects of the programme – to add to, to improve on, or to discard.

The important challenge is to understand why people join the programme, and why they do not. This can be done by evaluating, amongst other factors, the perceived worth of the HIV support group as the core entity of the programme. Interventions can then be made, and renewed efforts made to increase the numbers joining the programme earlier, reduce the percentage of patients on ARVs (while increasing the absolute number), and time the starting of ARV appropriately while the patients are still relatively asymptomatic.

In addition, the number needing ARVs on the Wellness programme hovers around 63%. Those that need the ARVs for their failing immune systems must have access to the medications, so the absolute numbers on treatment must consistently rise. As a percentage overall however, the number needs to decrease by testing and successfully recruiting on to the Wellness Programme, earlier in each individual's HIV lifecycle, before ARVs are needed.

An individual starting antiretrovirals at the optimal time improves by definition his/her HIV Wellness, and it is this last target outcome that links to the larger question of this research - whether membership of the programme directly or indirectly increases the wellness of an HIV positive patient (by his/her own understanding and perception) and which improvements to the programme will attract members earlier in the course of their disease.

## PROGRAMME DEVELOPMENT FROM 2005

There have been some published accounts describing aspects of the Madwaleni HIV Wellness Programme. In response, concerns were voiced as to the true accessibility of the programme. A programme poster exhibited in the 2006 Southern Africa HIV conference in Durban was entitled “One

patient lost to follow-up in 11 months – can we sustain it?"; an important reality at the time was that management was unaware that less than 20% of patients testing HIV positive were then joining the programme as members.

At the outset of the programme in 2005, staff visited three different HIV /ARV programmes (Lusikisiki, Queenstown, and Coronation Johannesburg) to decide on the Madwaleni programme systems and data collection requirements. Qualitative benchmarking at these sites gave the Madwaleni team an idea of what system might be successful at Madwaleni. Modifications to the system continue to be made, always at the initiation of the local health providers. It is also realized, in retrospect, that an article on the programme in the Southern African HIV Clinicians Journal (Cooke R., Wilkinson. L., 2005) paid no heed to choosing its goals and objectives by canvassing its clients for their views and opinions.

A recent analysis compared the Madwaleni HIV programme with others in the Eastern Cape and made the following observation (Clarfelt A., 2009):

*"The HIV programme at Madwaleni hospital is more of an institutional / top-down initiative rather than something that is community owned and run. Community participation is a consequence of the programme co-ordinator recruiting community members as adherence counsellors, or of going to the communities to consult traditional leadership in order to get co-operation. One clear indicator of this is that access to antiretroviral treatment is only attainable through membership of an HIV support group. This removes the choice from the individual / community to enter into group education centres, or, more poignantly, to disclose his / her HIV status if he / she is to get treated and ultimately survive. Interviews with patients revealed that HIV support groups were hospital rather than community run, meaning there is limited community ownership of the support groups:*

*Researcher: "Who is responsible for the HIV support group in your area?"*

*Patient: "I don't know, it is under Madwaleni."*

This assertion is contrary to management claims of having full community involvement. If the above assertions are true, there are weaknesses to rectify in the interests of improving membership figures. This realization is especially relevant when considering successful "living with HIV" is recognized to be associated with personal acceptance, disclosure and ownership of the disease, rather than a top-down, authoritarian and at worst coercive approach by a health institution.

Conducting a quality improvement project (QIP) includes assessment of structure, process and outcome criteria against specific target standards. In the case of Madwaleni, specific criteria were chosen based on medical evidence of their contribution to wellness. Choosing these criteria was originally done in 2005 by senior programme management. Evidence-based decisions were made resulting in certain criteria being decided on. No input was requested from the HIV population themselves, be they members or non-members. A quality audit conducted in 2006 specifically

evaluated these criteria, extending the analysis to identifying those reasons why individuals may be delayed from starting antiretrovirals longer than the chosen start date. Management is now uncomfortable that the outcomes have been chosen independently of client and member input.

There is good evidence for the merits of screening for preventable and treatable diseases; the literature particularly pushes for inclusion of a thorough screening for active/latent tuberculosis and cervical cancer (or precursors). A full one third of the world's population has been infected with TB, and while the lifetime risk of active disease in an HIV-negative individual is 10%, the same risk in an HIV-positive person is 10% per year. In addition, the incidence of cervical cancer is ten times higher in HIV positive women. Of the 17 million HIV positive women worldwide, numbers being screened for precursors to cervical cancer are inadequate, especially considering the little cost for potential huge benefit (Franceschi S. et al.). Apart from follow-up of those on antiretrovirals with "safety blood tests" and clinical screening for side-effects, standards of TB investigation, diagnosis and follow-up on treatment, as well as the coverage of cervical cancer screening are specific benchmarks of overall clinical standard.

As a health programme, no apologies are made for the outcomes being biased towards clinical criteria and targets. More needs to be done, in parallel, to understand the true needs and challenges of the people served by the programme. The establishment of the support groups, a Wellness programme, and the employment of HIV positive staff members are all attempts to transcend the patient-provider gap. There is good reason, despite these initiatives, to adopt the "know your customer" mantra in the interests of the long-term benefit of the programme.



## LITERATURE REVIEW

In asking the views and opinions of members and non-members alike, it is remembered that the backbone to the programme is the support group. The main objective of this review is, therefore, to look for evidence of the benefit of such forums as interventions in the field of health.

There are different themes evident in the literature concerning support groups and wellness programmes:

- Historical accounts of the first documented support groups focus on those started in Europe and North America.
- Many of the studies evaluating the efficacy of wellness or support programmes have focused on support for cancer patients – with an occasional review of those programmes available to other patients with other chronic diseases such as diabetes.
- When targeting specific knowledge on the efficacy of HIV+ patient support groups, the literature consists of two main themes. Firstly, arguments for their existence in the context of a theoretical model and furthermore, evaluations highlighting the differences/similarities between the groups.
- Identifying work done on the psychological aspects of HIV positive individuals “wellness” - studies on their thoughts, feelings, and fears concerning their HIV positive status.

With regards wellness programmes in general, the literature is scarce with respect to the role of lay people trained to be Community Health Workers (CHWs) and Peer Educators (PEs) in assisting with task shifting and service provision in rural resource-poor health care settings, and this research will hope to shed more light on this aspect of service provision in the Madwaleni context.

### EARLY HISTORICAL DEVELOPMENT OF SUPPORT GROUPS

The significant forerunner of today’s “support group” concept is recognized in the literature as the settlement house movement established by Jane Addas at Hull House in Chicago (USA) in the late 1800s. Educational groups and community action programmes helped the poor and unemployed to deal with social, economic and personal problems. The start of the science and practice of social work and psychotherapy then began with the turn of the century. The evolving continuum of groups for chronic disease patients ranged from open-ended, drop-in groups that provide supportive, educational or self-help group experiences to time-limited or closed groups using more psycho-educational therapy tools. (Fobair P., 1997)

Ida Cannon, a prominent social worker, published a book titled *Social Work in Hospitals* in the 1920s, detailing models of group therapy and described their usefulness for patients suffering from heart disease, diabetes, infantile paralysis, scoliosis and malnutrition. For physicians, the origins of group therapy began in hospital services for tuberculosis patients. A physician named Dr Joseph Pratt at

Massachusetts General Hospital in Boston (with whom Ida Cannon worked closely in the 1920s) included a home visits and diary keeping as well as weekly meetings for his “tuberculosis class”.

To quote from Cannon’s book:

“(group therapy helped) to develop a loyalty and cooperation which brings patients back to the clinic more ready to follow advice. It gives a sense of comradeship which is of great value. New patients soon lose their shyness, those consumed with self-pity seldom fail to find others making less of greater handicaps, and the discouraged man or woman hears how someone else gained when conditions seemed quite as helpless” (Cannon I.,1924)

Further to the work of Dr Pratt, the literature does not describe physicians leading groups as part of the care for patients with chronic diseases, rather the focus shifted to psychiatrists beginning to experiment with group methods with psychotic patients during the 1920’s and 1930s (Yalom D., 1978). It was from that period forward that the proponents of formal psychology and psychiatry began to shape the development of group processes.

### THEORIES OF PSYCHOLOGICAL SUPPORT

There are different psychology theories that have sparred, competed and collaborated together during the 20<sup>th</sup> century:

1. Systems theory
2. Behaviourism
3. Freudian psychoanalysis
4. Existentialism
5. Coping Theory
6. Social Bonding Theory
7. Postmodernism

A brief outline of each of these schools of thought as detailed in the literature follows:

#### Systems Theory

Systems theory is an important framework within which potential benefits of support groups can be explained. Systems theory depicts the group as a “system” that has a defined boundary and interrelated parts. The group is viewed as helping participants adapt to external conditions and to characteristics of individual participants that confront the group system (Schopler J., Galinski M., 1993). The importance of the group leader is strongly acknowledged, who in turn acknowledges the influence of the larger system on patients. Group forces promote two kinds of internal group leadership: task oriented and social-emotional – both are important to the development and

maintenance of an ongoing group. Smaller groups are favoured over larger ones – a positive outcome of small-group forces is group cohesion.

### Behaviourism

Founded by John Watson in the early part of the 20<sup>th</sup> century, behaviorism holds the view that all psychology must be linked to the relationship between stimuli and behavior, both of which must be measurable. The theory holds therefore, that mental states cannot form the object of observation, as speculative questions as to the elements of mind cannot be objectively answered. Proponents argue the introspective study of conscious experience is wholly unreliable and unproductive. Support group attendees, as possible subjects of research, would be uncomfortable in the knowledge that – in the words of John Watson – “behaviourism recognizes no dividing line between man and brute...” (Watson J, 1913) Later proponents at least acknowledged the existence of the mind, but gave little credence to thinking and emotion as the causes of behavior.

The literature is clear that simple phobias are the optimum arena for the most valid application of traditional behavioural theory and therapies. Use of behavioral modification theories is also applicable in those with learning disabilities. More complex illnesses such as depression are not easily handled within the boundaries of behaviourism alone, but the modern approach of cognitive behavioural therapy is now a well-established, effective tool in group therapy.

### Freudian Psychoanalysis

Freudian psychology places an emphasis on the role of biological drives in human development, whereby the patient / group member verbalizes thoughts, including free associations, fantasies and dreams, from which the analyst formulates the unconscious conflicts causing the patient's symptoms and character problems, and interprets them for the patient to create insight for resolution of the problems. The most common problems treatable with psychoanalysis include: phobias, conversions, compulsions, obsessions, anxiety attacks, depressions, sexual dysfunctions, a wide variety of relationship problems (such as dating and marital strife), and a wide variety of character problems (Freud S. 1953).

### Existentialism

The philosophy of existentialism is another theory that has been applied to group therapy. Proponents believe that the main issue that human beings must deal with is the cognitive need to give meaning to their lives; existentialism holds the view that the essence of the human being is to exist, but it is vital there is some meaning to this existence, for fear of insignificance. This theory emerged in the 1940s as a major development in American psychotherapy, alongside Watsonian behaviourism and Freudian psychoanalysis (Yalom D., 1978).

Conversely to Freudian theorists, existentialists conversely take a non-judgmental attitude towards patients' previous decision-making and openly function as role-models by sharing more of themselves. People's awareness of the limits of our own existence can inspire polarizing extremes of emotion, which encourage us to evaluate the meaning of life.

Four important themes appear in reviews of existentialism: death, freedom, isolation, and meaning.

- **Death**  
Avoiding the thought of one's own death can lead to anxiety and to defences such as an irrational belief in one's own "specialness" or in an ultimate rescuer. Specialness make take the form of workaholism, narcissism, or a drive for money or power, and the wish to be rescued from the edge of the abyss by an omnipotent presence is pervasive in human culture. Both irrational beliefs represent efforts to gain control over the fear of one's own death.
- **Freedom**  
Freedom refers to the absence of external structure. Individuals are responsible for creating their own world and life design and for their choices and actions. Their responsibility is to discover the choices one has to further one's potential and to create meaning in one's life.
- **Isolation**  
Existentialist isolation refers to the need to enter and exist in life alone no matter how close one comes to one another.
- **Meaning**  
In a universe that has no meaning, one must construct our own meaning in life, as pointed out by such well-known philosophers as Jean-Paul Satre in the 1940s.

To bring these concepts together in context, the literature recognizes that the debate around the efficacy of any support group is fuelled by the tension between a person's wish to be part of the larger whole - to have intimate contact with others – and the awareness that, ultimately, one is alone and isolated, albeit by the same token, "special" as an irrational defence against the anxiety around the thought of death.

### Coping therapy

Two principle strategies for coping around stress are recognized in coping theory (Lazarus and Folkman, 1984): problem-focused coping, which aims to change objective aspects of the problem; and emotion-focused coping, which aims to manage emotional stress associated with the problem. Because men are problem-focused and action-oriented, a support group that focuses on solving practical problems may be more acceptable than a traditional support group that focuses on emotions (Adamsen L. et al, 2001).

### Social Bonding Theory

Social Bonding theory is rooted and derived from the General Theory of Crime (Hirschi T., 1969); however it is of relevance to a discussion of the Madwaleni community and support groups for its interest as a way of approaching social problems.

The four basic elements of social bonding theory are attachment, commitment, decisions regarding choices made between the “right” and “wrong” activities, and lastly the common value system within an individual’s society or subgroup. Attachment is described as the level of values and norms that an individual holds in society. Attachment is especially important when it come to the person’s parental figures. This theory suggests that conventional figures, most importantly parents, but also peers and school colleagues, make a huge impact on positive development, just as long as these ties are positive and do not deviate from the social norms of society. Consistent evidence shows that attachments to family shape the commitment to activities, social life, and social location (Hartwell SW., Orr K. 1999).

As for commitment, this can be described as the level of commitment that an individual has to abide by legal behavior, understanding the difference between “right” and “wrong”, which should be learned early in life with the positive influence of society (Burton et al, 1995). In addition, the “bond” between mother, father, and child in a normal nuclear family, is very strong, this in turn makes a blue print of an entire adult life on the child, thereby influencing the foundation of the individuals choice and behaviour.

Lastly, when examining the bonding theory around “wrong” behaviour, if a person shares common values/norms as others in their subgroup then the motivation to deviate will be hard to overcome.

The theory proposes that should society make as much of an effort as possible with maintaining family ties and bonds, focus on building schools’ social and educational impact on children, and lastly facilitate the environment for social bonding (specifically regarding the provision of low-cost housing and other infrastructure in poorer areas), then the greater proportion of individuals will grow to be productive individuals conscious of the importance developing that same society in a self-perpetuating manner.

### Postmodernism

Postmodernism is a linguistic theory proposing that the world is more than a tangible, objective system – proponents such as Michel Foucault hold the view that each support group attended is responsive to the group culture’s use of language and power (Burrell G. 1988). How one knows and what one believes is connected to language. Truth is a product of language rather than something that is objective and universal. Social reality defines how one conceives and defines it. The group creates its own culture as each participant interacts with one another. Group members substantiate their

realities by constructing and interpreting values, beliefs and commitments through storytelling, thereby developing the group's narrative. As succinctly described in 1994, "social groups invent their own community identity much as individuals create their own personal identity" (Pardek, Murphy & Choi 1994)

#### GROUP THERAPY – MEMBER-DIRECTED VS PSYCHO-EDUCATIONAL

Both evaluations of member-directed support groups and psycho-educational groups are found in the literature. The former is defined as a forum in which members share a primary focus on the expression of emotions and the building of social support. The nature of group discussion is traditionally open and non-directive. Psycho-educational groups consist of educational sessions on stress-management strategies (problem-solving, goal setting, relaxation, body image/sexuality, effective communication and cognitive techniques) and activity management (encouragement to increase recreational and physical activities).

A summary of the main studies on support groups in the late 20<sup>th</sup> century is provided below (Fobair P., 1997):

HEALTH CHALLENGE	RESEARCH	QUANTITATIVE INSTRUMENT	OUTCOMES
<b>SUPPORTIVE GROUPS</b>			
Newly diagnosed breast cancer	Farash 1977	Beck Depression Inventory Score, Rorschach test	No significant difference in outcome versus control (NS)
Metastatic Breast Cancer	Spiegel, Bloom & Yalom 1981	Profile of Mood States (POMS)	Significant outcomes (S) compared to control (only at 300 days)
Hodgkin's disease	Jacobs 1983	Cancer Patient Behaviour Scale	NS
Radiotherapy	Forester 1993	Schedule for Affective Disorders and Schizophrenia (SADS), ) "emotional symptom score"	NS
<b>PSYCHOEDUCATIONAL</b>			
Lung/Colorectal/prostate cancer	Heinrich 1985	SCL-90-R, Psychological Adjustment to Illness Scale (PAIS)	NS
Newly diagnosed gynaecological cancer	Cain 1986	Hamilton Depression and Anxiety Rating Scales, PAIS	S
Malignant melanoma	Fawzy 1990	POMS, dealing with Illness Coping Inventory	S
Primary tumours	Berglund 1994	Hospital Anxiety & Depression Inventory (HADS), Mental Adjustment to Cancer Scale (MAC - Fighting Spirit subscale)	S
Early stage breast cancer	Samarel 1997	POMS Linear Analogue Scale, Symptom Distress Scale	NS
<b>PSYCHOEDUCATIONAL VS. SUPPORTIVE</b>			
Mixed diagnoses	Cunningham 1989	POMS, SCL-90-R	Psychoed. significantly

			better outcomes
Mixed cancers	Telch 1986	Structured clinical interview, POMS, Perceived Self-Efficacy Scale	Psychoed. significantly better outcomes
Depression and Stage 2 cancers	Evans 1995	SCL-90-R	Supportive significantly better outcomes
Distressed patients with various cancers	Bottomley 1996	HADS, MAC	Psychoed. significantly better outcomes
Stage 1,2,3 breast cancer	Helgeson 1999	Medical Events Study, Positive & Negative Affects Scale, Impact of Events Scale	Psychoed. significantly better outcomes
Primary breast cancer	Edelman 1999	POMS, Functional Living Index – Cancer, Rosenberg Self-Esteem Inventory	Psychoed significantly better outcomes

**Table 2. Summary of quantitative evaluations of efficacy of support groups in chronic disease**

The paucity of methodologically-sound evaluations of the effects of the participation in the support groups is clear in these dated studies. More recently however, there has been more evidence to suggest the “traditional” support group has been effective in assisting patients in reducing distress or improving outcomes on other psychological criteria. This is despite the earlier studies demonstrating psycho-educational interventions faring better when the two forms of groups have been evaluated against each other. The important difference however, is that a group leader is now accepted as crucial to directing and influencing participants and ultimately outcomes.

For being the most studied topic in the literature – as borne out in the table above - breast cancer deserves individual mention. Breast cancer is one form of malignant disease that has attracted concerted efforts to support and treat the disease, not least owing to the thousands suffering from the disease. A significant body of work has been done examining the success of support groups for these patients, studying the (ultimately favourable) survival improvements after psychosocial treatment of patients with metastatic disease (Spiegel D., 1984). More recently, the work done under the administrative umbrella of Breast Cancer Care in the United Kingdom has led to the emergence of a network of self-help support groups through the C4Ward initiative, an alliance of group members, supportive professionals and volunteers (McLeod E., 1998). In keeping with the more recent successes with traditional but facilitator-led support groups, published and unpublished accounts of these activities suggest that lay/professional alliances play a key role in developing the groups that constitute an important source of mutual support in promoting women’s well-being. It was agreed amongst group members that the contribution of the facilitators in helping to build group interaction was of critical importance. Women reported “increased resilience to symptoms, a calmer attitude to death, a greater access to information and a greater capacity for enjoyment” as a result of these support groups.

## DISCUSSION OF HIV WELLNESS AND SUPPORT PROGRAMMES.

### Arguments for the existence of HIV Wellness Programmes

Arguments for the existence of HIV Wellness programmes center on the providing of information, understanding, and acceptance for members. Authors make a clear distinction between the specific needs of PLWAs (People Living With HIV/AIDS) and those with other chronic illnesses, citing the higher prevalence of uncertainty of HIV/AIDS, living with the fear of dying, living with anxiety and hopelessness, living with bereavement, trying to counteract stigma and isolation, and living with addictophobia in society (Spirig R. 2008). Experience suggests that all of these needs are common to the Madwaleni HIV community, with the possible exception of the last, namely addictophobia (and the associated substance abuse).

Low health literacy in HIV positive individuals is both a barrier to effective self-care and an added stress (Devereux J., Porche D.J. 2004); it is vital that a relevant HIV Wellness Programme maintains and expands the gains in literacy, and the community understanding as a consequence.

The backbone of the Madwaleni HIV programme is membership of an HIV support group. In the literature, it is commonly assumed that support groups in general are helpful for PLWAs without having been evaluated (Spirig R., 2008). There is very little evidence in the literature of objective, scientific evaluation of the benefit of HIV support programmes. This is especially true where comment is provided on the value of the support group entity itself. Just as the Madwaleni programme is currently embarking on substantial funding partnerships in 2007, studies done in the US as early as 1998 pointed to the scarcity of financial resources requiring documentation of the effectiveness of interventions (i.e. support groups) being required by such funders (Spirig R., 2008). This formal evaluation of effectiveness is severely lacking.

The literature clearly demonstrated that there is often a lack of scientific theoretical basis for the support group interventions. Many articles included a conceptual basis more as an afterthought on which to develop and evaluate the efficacy of the support group intervention. Certain of the articles could be classified as clinical notes, to the extent that they do not include a formal evaluation of intervention (support group) outcome (Spirig R., 2008<sup>19</sup>). The latter article did still provide valuable insights into examples of structures and processes employed in the use of support groups. Where an evaluation was done, audio-taped sessions, process notes of facilitators, and experiences of the participants were used to identify therapeutic elements, the value of the groups and the problems in the implementation process (Foster SB., 1994).

A notable exception to the lack of conceptual backgrounds in research is the regular reference to the Pender Health Promotional Model (Mendias EP., Paar DP. 2007). Pender's hypothesis refers to demographic and biological characteristics affecting health-promoting behaviors indirectly through



mediating cognitive-perceptual variables. The former characteristics are age, income, marital status, education, and body mass index. The three variables are self-actualization, interpersonal support and health responsibility. Studies into subjects as diverse as health promotion in smoking, irritable bowel syndrome and medication adherence were referenced. All three of these variables are of relevance in the Madwaleni context, and a key requirement of this research will be assessing the impact of the HIV programme on equivalent variables in the context of the local HIV community characteristics.

Choosing process and outcome standards to a Wellness programme is determined by both the available evidence and practices at more experienced HIV sites. One of the mainstays of HIV care is antiretroviral medication. Support for an ongoing health care worker – patient relationship is provided by a Cochrane review in 2007 that found evidence for the effectiveness of patient support and education interventions intended to improve adherence to antiretroviral therapy (Rueda S. et al 2007). Interestingly, while interventions targeting practical medication management skills, interventions delivered over 12 weeks or more were associated with improved adherence outcomes. Those interventions administered to individuals rather than groups were associated with similarly favorable outcomes. Research has shown that a patient needs to be at least 95% adherent to antiretroviral medication to limit the development of viral resistance (Paterson DL. et al, 2000).

Early work in the United States into Wellness programmes suggested general psychosocial needs are met simply through interpersonal contact. Recently, however, three distinct types of social support have been recognized: emotional support, informational support and interventional support (Kalichman S.C., 2005). The literature clearly demonstrated that where the practice of social support within HIV programmes was extended to include “interventional” support this largely remained non-clinical. This is not to say the clinical support did not exist – rather there is little evidence that it is provided within the wellness programmes themselves.

Some readings also demonstrate the usefulness of HIV support programmes on the basis of a proven theoretical, conceptual background rather than practical observation. The latter is often more relevant but has the disadvantage of being applied in hindsight where there is no formal prospective study done. The work done suggests that the Madwaleni support groups might be tested for success or failure in each of the following areas, as highlighted across different studies: reduction of stress (including work on psycho-neuroimmunology), greater empowerment, increased social support, increased group support and improved quality of life (Spirig R., 1998). Each of these is defined according to strict definitions to be universally understood:

- Stress: a particular relationship between the person and the environment that is appraised by the person as taxing or exceeding his or her resources and endangering his/her well-being
- Empowerment: a process by which people are supported and valued as they learn about themselves, make decisions, mobilize resources, and accept power, control, and direction of their lives
- Social Support: emotional support, informational support and instrumental support

- Group support: all studies defined this in term of the physical group setting in which the social support occurred
- Quality of life: a person's sense of wellbeing that stems from a person's satisfaction and dissatisfaction with the areas of life important to him or her.

Notably there were few studies that defined the specific intervention tools used in group therapy. It was simply stated that people within cohesive and interacting groups are more self-accepting. There are, however, outcome-based studies recognizing the correlation between each of the following: support group non-attendance and higher stress (Kalichman SC., 2005), social support and improved quality of life (Nunes JA. et al, 1995), and support group attendance and decreased drug taking (Greenberg JB. et al, 1996)<sup>7</sup>.

Qualitative work has identified three different support group attendees: long-term attendees, short-term attendees and non-attendees, with different themes identified for each with regard to their support group experiences (Sandstrom KL., 1996).

The durability of patient perceptions was recently demonstrated in a survey of African HIV positive immigrants to the UK (McMunn AM. et al 1997). Its purpose was to establish the reasons for the majority accessing health care so late. What was remarkable in its own right was that the home country experience and community mobilization was highly influential on HIV awareness, appreciation of risk, and attitudes to health services. Of the institutional barriers recognised, a lack of cultural understanding, lack of open access or community clinics, and crucially - a failure to integrate clinical care with support organizations.

The objectives of this research will omit formal evaluation of the efficacy role of alternatives to "western" HIV programmes, specifically traditional healers and their treatments, but their role in affecting membership numbers on the programme will be noted. A recent study in Thailand showed that being open about one's HIV status to one's community is positively associated with receiving modern treatment for HIV-related ailments, that being female is negatively associated with receiving modern treatment and that living in a rural area (as opposed to living in an urban area) is associated with using herbal remedies (Vanlandingham M. et al, 2006). That traditional medicine has an important influence on community acceptance of a "modern" HIV programme in rural Transkei is without doubt.

There are many studies focusing on rural support programmes, but the relevance remains limited since they are based predominantly in the United States. Where the studies are evaluating community-based programmes (Harris GE. 2006; Mamary EM. et al 2004) rather than strictly rural, there is more common ground.

A study in the United States highlighted seven issues that are important to consider when establishing a rural HIV support group (Mamary EM. et al 2004). Among them were some that demonstrated the

vast difference between rural challenges in the States compared to here. Specifically the use of newspapers to introduce the support group to the community is extremely relevant but only highlights the lack of services (of any kind) in the deep rural areas of South Africa. The rural setting of HIV in South Africa offers a unique set of challenges, with the attitudes of rural South Africans neatly outlined in some local studies (Anderson DB., Shaw SL., 1994).

#### Discussion of differences and similarities between HIV Wellness groups

Reason for forming support groups is fuelled by the belief that programmes targeting specific subpopulations of People living with AIDS (PLWAs) are essential because of their different needs (Spirig R. 1998). Owing to the demographics of the HIV population in the first world, most support programmes in the US focus on men and gay men in particular (Bor R., Tilling J. 1991). The remainder focuses on women and – in keeping with the above trend – lesbian women (Foster SB. et al 1994). Interestingly, only one exception includes mainly African-Americans (Kalichman SC. 1996)<sup>11</sup>. There is also evidence of some support groups formed for those alongside a parallel group for those living with AIDS. Neither of the last two exceptions includes any rigorous evaluation, relying only on description of broadly defined interventions.

By far the most studies on HIV support programmes are set in the developed world. A Cochrane review published as recently as 2006 aimed at evaluating the association between the setting and organization of care and outcomes for people living with HIV and AIDS included no studies found from the developing world (Handford CD. et al 2006).

One study concluded their psycho-educational tool is an effective support, especially when addressing the needs of individuals recently tested HIV positive, but included only clinical notes as discussion (Coleman VE.; Harris GN. 1989).

An interesting comparison was made in one study between a structured closed, time-limited group as opposed to an on-going, open, drop-in group. In practice, the latter grew out of the first more structured approach and seemed the most promising structure (Foster SB. et al, 1994). An important caveat to this finding is that the groups focused on lesbians; this additional bond outside of their communal HIV status may have contributed to the success of the structured support group.

A South African study conducted in Tshwane (Limpopo) was one of the few to first link the needs of the group (HIV positive pregnant women) to the interventions provided (Visser N. et al, 2005). The intervention of a support group on consenting HIV positive pregnant women was evaluated quantitatively against a control group (those who declined attendance at the support group). This intervention was evaluated in terms of the impact on participants' levels of personal depression, self-esteem, disclosure, coping, social support, stigma, perceived community stigma, and knowledge. Qualitatively, participants' feedback of the support groups was evaluated to augment the results of the quantitative analysis. Findings of the research indicate that the intervention group showed significantly

higher positive coping, self-esteem, levels of positive support, and disclosure compared to the control group. Interesting results were found regarding depression and knowledge levels, but these were not found to be significant. No differences were identified between the groups in terms of negative coping, negative support or the experience of stigma. Regular feedback allowed adjustments to programme material in accordance with need.

## COMPARISON OF QUALITATIVE RESEARCH METHODOLOGIES

Formal consideration of which methodology to apply to this study is assisted by the literature. The latter is however, clearly stacked in favour of uncovering non-South African studies, and the differences between cultures and settings are stark. When considering a methodology centered on the use of questionnaires, there are certain standard scales of response that may be applicable. These include the Likert Scale (Heine SJ. 2002), Weinerts Personal resource questionnaire, and Ferrans and Powers quality of life index (Nunes JA. 1995). There are however potential cultural differences in response, where people from one culture are more likely to answer toward the center of a scale than are people from another. Similarly, the reference effect is the confounding role of context in comparisons of mean questionnaire responses across different groups. By implication, caution must be exercised in applying questionnaire-based study design to the assessment of Madwaleni Wellness programme. There is literature to assist in keeping the relevance to the local settings, but the scarcity of South African examples of questionnaire-based research amongst impoverished, uneducated and often illiterate communities suggests the questionnaire data collection tool provides limited benchmarking opportunities.

Importantly, there is little evidence in the literature of support groups tied to medical support as the Madwaleni programme is structured. The Madwaleni programme has different interventions occurring within or without the literal group of patients meeting once a week. It follows therefore that any research methodology should capture the uniqueness of the Madwaleni programme.

For these reasons, the focus group forum is preferable, where the support group can double as a focus group forum for qualitative research into HIV Wellness programmes, especially where the support group is a manageable size (Bor R., Tilling J. 1996; Foster SB. et al 1994).

Little consideration was found in the literature, however, for including these clinical screening processes specifically as part of an overall package of care, as opposed to the merits of the individual clinical protocols.

## **CLARITY OF DEFINITIONS**

As is evident from the literature, it is important to be clear on the meaning of “support group”, “support programme” and “HIV Wellness programme”. The above literature review differentiates between support groups and the psycho-educational groups – the latter being the forum for more interventions

on the part of the health professional. The Madwaleni HIV programme support group will be more loosely defined in this research; the research exercise will look to clarify what is the nature of the support group, differentiating between the partly subjective understanding of this definition by different members, non-members and health professionals alike.

Furthermore, the HIV Wellness programme is seen as a larger group of health services offered to the members, one of which is the support group providing different emotional, educational, and psychological support and interventions. It is the nature of these interventions that distinguishes a group from a programme.

HIV SUPPORT GROUP with interventions within group from peer educators/counselors

HIV PROGRAMME with interventions outside of the support groups by professionals

Where the intervention occurs within a support group setting, the entity to be evaluated remains the support group. Where there is a further service/intervention provided by professionals/peers (e.g. one-on-one counseling, or pap smears for support group members), the entity then graduates to meet the programme definition. To that extent, the phrases “wellness programme” and “support programme” can be used interchangeably, as borne out by the literature.

Those individuals participating in the focus groups are referred to as “participants” whereas an individual is referred to as a “member” if on the Madwaleni HIV programme.

## RESEARCH AIM

The purpose of this research was to obtain an in-depth understanding of individual's perception of the success of the Madwaleni HIV Wellness Programme in the context of the individual needs in living with HIV.

## RESEARCH OBJECTIVES

The objectives were as follows:

- To determine the factors influencing HIV positive individuals to join or not join the Madwaleni HIV Wellness programme.
- To assess the community understanding of the programme in the context of the community lived in, including the perceived priority health and social problems in the Madwaleni/Mbashe community.
- To recommend modifications to the existing outcomes by which the success of the Madwaleni HIV programme is determined, in light of the information gained by the first two objectives listed above.

## **RESEARCH METHODOLOGY**

### **QUALITATIVE STUDY DESIGN AND METHOD**

The qualitative study design used open-ended questions in a number of focus groups of study participants. Individual interviews were held with participants where stigma concerns and/or non-membership of the HIV programme precluded participation in a focus group.

Since the narrative captured during a focus group provides the necessary material for analysis of subjective opinion and perception, this chosen study design has advantages over a more in-flexible questionnaire-based study in this poor, uneducated community. Illiterate individuals comprised a large percentage and could not be excluded. Furthermore, staff-administered questionnaires were inappropriate because the lay counselors/peer educators (who would capture any questionnaire information) are themselves often illiterate or semi-illiterate. Open-ended discussion facilitated the forethought and consideration conducive to discussion and that is easier in a collective group in the traditional Xhosa setting of this deep rural area. The study design of focus groups allowed the facilitator to rephrase questions where uneducated participants responded inappropriately, rather than inaccurately.

Participants were encouraged to all participate freely and there remained a freedom to express their ideas in their own words. Each focus group had a time limit of 1.5 hrs, as longer periods were likely to be unproductive.

Focus group transcripts provide opinion and thought, but often not context. Accordingly, quantitative data suitably collected in a questionnaire-based research exercises by this author and an elective medical student in the Madwaleni community earlier in 2009, was used to enrich and validate the themes (and discussion thereof) emerging from the focus groups (Winkel C, Cooke R, 2009). This information provided largely demographic data, so providing a good backdrop for analysis of the transcripts; information was particularly complementary to the focus group material when concerned with the community access to health care in such a poorly- developed area.

There were some population groups within which canvassing opinion using the focus group tool was difficult because of stigma and the uneasy participation. Some individual interviews were held to allow for their participation.

### **STUDY POPULATION AND SAMPLING**

Purposive sampling of the total Madwaleni-Mbashe population was conducted to form focus groups; the groups were labeled:

GROUP A      HIV team staff members (HIV positive and therefore Wellness members) and support

	group members at Madwaleni
GROUP B	HIV support group members at Xora Community Health Center (down-referral for Madwaleni patients)
GROUP C	HIV positive members not joining the programme (and not on ARVs)
GROUP D	Former Wellness programme members lost to follow-up and then “found” and/or those members who are no longer members for having “dropped out”.
GROUP E	Community Leaders

Individual interviews were held for those in Groups C and D where there was a clear reluctance to take part in a discussion forum of a focus group for reasons related to stigma and/or privacy.

#### Exclusion criteria

Children on the wellness programme and on ARVs were not included in the sample although the adult participants included them as a focus group topic if they wished.

A distinct group of members excluded from the research sample is that comprising patients who joined the programme while in-patients. This research is concerned with the HIV programme as an outpatient programme for members choosing to join and access care frequently. There is a documented lost-to-follow-up rate for ARV patients started on medication as an in-patient that is three times as high as the programme average overall (Cooke R., Wilkinson L., 2007). Such a serious problem requires special attention as a separate initiative, although parallels with these in-patients were drawn to aid the discussion.

PMTCT (Prevention of Mother to Child Transmission of HIV) singles out pregnant HIV positive women as different since they are often fast-tracked onto the programme to begin ARVs, so they were also excluded.

Further research is required to analyse the perceived programmes benefits and dislikes for these patients.

#### SAMPLING: GROUPS A AND B

Name	Madwaleni Hospital	Xora CHC	Soga PHC	Nkanya PHC	Mqhele PHC	Melitafa PHC	Bomvana PHC
Wellness Members (08/2009)	2028	757	223	223	194	120	215

**Table 3: Total number of HIV Wellness members by health facility**

CHC = Community Health Center, PHC = Primary Health Clinic

The total of HIV staff at Madwaleni is 28. 20 of these are lay people who are either HIV positive members of the programme employed fulltime or community health workers (CHWs). There are five community health workers working at each clinic. Group A comprised both HIV positive staff members, and other regular support group members.

Group B is essentially the same as Group A – with the crucial difference that participants were selected from those HIV positive staff and members at Xora Community Health Center, rather than Madwaleni district hospital.

#### **SAMPLING: GROUP C**

Names and contact details of those testing positive for HIV at VCT outreach are recorded in a confidential VCT register. It is therefore possible to identify those not on the programme. A small sample of these were selected on a random basis, stratified for age and gender to specifically include males and the age group 15 – 24 in particular; these two demographic categories are associated with the least representation as members of the HIV programme.

#### **SAMPLING: GROUP D**

A member is classified as lost-to-follow up if he/she has not attended a support group for the last three months. The Madwaleni HIV programme currently has a lost-to-follow up rate of 3% among outpatient ARV members. There are a number who are classified as lost- to follow up, but whose whereabouts is known to the HIV programme staff. A small sample of these individuals were approached and interviewed individually.

#### **SAMPLING: GROUP E**

The group of community leaders has to be consulted for any such research process as part of the stakeholder management so important to any community-oriented primary care initiative. There are an estimated 40 chiefs and headmen whose subjects form the Madwaleni catchment population. They meet monthly with the Queen of the Bomvana Clan at the Great Place. Their collective knowledge and approval of this research initiative is crucial, while they also provided information as research subjects themselves.

This group of community leaders needs to be canvassed as a matter of correct protocol outside of any perceived research benefit. The principal investigator was present at this meeting. Feedback to this same group after the research is equally very important.

### **PROCESS OF DATA ANALYSIS**

The focus groups were recorded with the assistance of a media communications consultant living on



site at Madwaleni. They were then forwarded to the Ilwimi Center of the Department of Linguistics, University of the Western Cape, South Africa, where they were transcribed and translated into English from the spoken Xhosa.

The transcripts were read and the emergence of patterns and themes were noted, within the framework of the ATLAS.ti, a scientific software tool designed to assist qualitative data analysis. In general, the basic elements of Grounded Theory were applied to the research process. Grounded theory is a systematic qualitative research methodology in the social sciences, emphasizing generation of theory from data in the process of conducting research (Strauss & Corbin 1990).

The basic elements of grounded theory consist of the generation of themes that impact on each other through cause-and-effect relationships. The basic building blocks of general themes are concepts that are identified in the transcripts. Concepts were used as the basic units of analysis, to name similar phenomena with the same term when comparing the comments and opinions given by focus group participants.

Higher level, more abstract themes were then generated through the same analytic process of making comparisons to highlight similarities and differences used to produce lower level concepts. As the “cornerstones” of developing a theory, these themes were then used to identify concrete answers to the question of why people do or do not join the HIV programme, so meeting a key research objective.

Each of the generation and development of these concepts, categories and propositions was an iterative process, aimed to inductively assist in the emergence of a theory around the joining/not joining of the Madwaleni HIV programme.

Those well-schooled in the application of Grounded Theory will be dismayed at the use of pre-research literature review. They will argue that studying the literature of the area under study gives preconceptions about what to find. Similarly, the use of recorded interviews/focus group discussions would be frowned upon; this is not normally practiced when applying Grounded Theory. This research, however, makes no claims to be a perfect example of the application of Grounded Theory. Aspects of the theory have been “borrowed” as a logical and ordered approach to categorizing the data.

By identifying a theory encapsulating the positive and negative factors influencing HIV positive members to join the programme, as well as identification of the key contextual factors relevant to the Madwaleni community, discussion then logically progressed to include ways to adapt the programme framework, activities, and target outcomes to be more demand- oriented and member-focused.

In the case of individuals from Group C and D (Non-/Infrequent members), participants were uneasy with the presence of a laptop and stand-alone microphone. These were therefore abandoned and a

small hand-held tape recorder was used to record the individual interviews and the small focus group for Groups C and D respectively.

Name	Madwaleni Hospital	Xora CHC	Soga PHC	Nkanya PHC	Mqhele PHC	Melitafa PHC	Bomvana PHC
Wellness Members (August 2009)	2028	757	223	223	194	120	215
Focus Group No.	3 (A and D)	1 (B)	0	1 (E)*	0	0	1 (pilot)
Focus Group (size )	13 (A) 7 (D) 5** (C)	15		6			12

**Table 4: Number, size and location of focus groups and interviews**

\*arbitrary venue for focus group with chiefs of different areas, not only of Nkanya area

\*number of individual interviews

## PILOT PROCESS

A pilot focus group was held at Bomvana clinic in January 2009. There is no known difference between this clinic population and those served by the other primary health clinics. Importantly however, Xora Health Center is an exception as a bigger community health facility serving a more urban population of Xora town itself.

The objective of this pilot exercise was to gain practical experience in conducting a focus group, as well as piloting the conceptual coding in analysis. The group was conducted in Xhosa by the chosen facilitator. It also served as an opportunity to train the facilitators for the upcoming focus groups held in isiXhosa in the absence of the principal investigator.

Examples of questions piloted at the focus group during the preparatory stage were:

1. What is the Madwaleni HIV wellness programme and what is its purpose?
2. Why did you join the HIV Wellness programme?
3. What are the main benefits of being a member?
4. What are the main disadvantages??
5. What are the important improvements to the programme you would like to see happen?
6. How confident are you these changes could be implemented and why?
7. Are there any groups in the community for whom it is more difficult to join the Wellness programme and why?

## DATA RELIABILITY AND VALIDITY

While a systematic analysis of the transcripts was done using a conceptual coding, the constant comparative method (Strauss & Corbin 1998) was employed to validate data – both in the field particularly when conducting individual interviews and when reviewing the initial coding of concepts, categories and propositions in the transcripts.

As envisaged, focus group A was conducted from a higher, more comprehensive level of understanding as the participants are both staff and programme members. Including staff members in focus groups assists with the reliability and validity of data, given they:

- Are the most knowledgeable group concerning the programme and HIV/ARV
- Are staff members who are HIV positive themselves
- Run the support groups at the primary health clinics (PHCs) on a weekly basis (Wed/Thurs) after the main support group at Madwaleni every Tuesday.

A regular Monday meeting with the staff helped to coordinate all the staff members' involvement and improve potential validity in the different focus groups. The same facilitators led each focus group, enabling validity of results to be sought through standardization of approach. The facilitators were trained to identify and record any area of bias as identified during the sessions.

The concern that participants may be negatively influenced by the “boss image” of the principal investigator who is the Chief Medical officer of the Hospital was validated during the focus group conducted at Madwaleni Hospital, so his presence was limited to that focus group and the individual interviews.

The HIV positive counselors wore both a “staff hat” and “patient hat” during the focus groups. The latter role is important to establish their objective views on other patients' subjective thoughts, feelings and ideas, but care was taken to recognize any positive bias towards the programme by staff members, as well as ensuring non-staff members were free to discuss points of view despite the presence of staff members.

The reliability of the focus groups is strengthened by the support group structure as a strong, established forum – all members are used to good interaction between the health professionals/lay counselors and themselves. Caution was exercised in the focus groups however, if the participants are used to a “lecture-listen” format of imparting health information, and they were encouraged to warm to doing the talking in focus group forum.

The groups of HIV positive non-members (C) were selected by comparing the VCT register with the database support group membership list. A sample of persons in the first list, but not reflected in the second, was chosen. As expected, this group of HIV positive non-members was interviewed as

individuals, as they were less comfortable to participate in a focus group – which on first appearances is mirrors the programme support group they have chosen NOT to join.

Group E (community leaders) were a difficult group to canvass, but necessary as part of good stakeholder management. The researchers were both politically and ethically required to inform the community leaders of the intentions to conduct the research, but also the community leaders contributed valuable information regarding their own perceptions of the HIV programme, and also opinions on the likely perceptions of the community members.

## ETHICAL CONSIDERATIONS

The rural uneducated Xhosa communities are vulnerable to inadequate understanding of the purpose of this research. Rigorous attention was paid to each person's full understanding of the merits of the research itself, as well as the opinions and thoughts they disclosed. Prior to conducting the focus group discussions with the members/non-members of the HIV Wellness Programme, a written informed Xhosa consent form (Appendix 3) was explained and signed by each person specifying:

- the aim of the research;
- the process of this research and the role of each participant;
- that anonymity will be respected by not referring to individuals by name in writing up the research. they will be addressed as a group and each could withdraw from the research process at anytime;
- prior to making the research public, that community-based feedback workshops will be conducted;
- the protection of intellectual property through acknowledgement of their contribution to the research during academic presentations and publications and that information would not be utilised for personal gain.

Some patient file information (Appendix 2) was used to supplement the analysis and discussion of the focus group transcripts results. The use of this information did not require consent to view the files retrospectively because there will be no disadvantage to the patients or their relatives, nor any compromise to their rights and dignity to an extent unreasonable and unjustified.

The involvement of the community itself was a unique experience that enriched this research. Patient advocacy is poor in this deeply rural, traditional society, independent of the HIV status. Empowering the community members to give opinions, discuss peers input and recommend programme modifications will hopefully have a lasting positive effect on the individual and collective voice.

Signed acknowledgement of informed consent ensured as well that no person under the age of 18 years participated.

Furthermore, including a focus group of HIV-positive staff members was vital to promotion of the principles of bottom-up management, flat hierarchy, and inclusionary teamwork so important to the evolution of the Madwaleni HIV programme.

## RESULTS AND ANALYSIS

The objective of presenting the results and preliminary analysis in a clear and logical manner is achieved by:

1. Identifying the key concepts that emerged from the transcripts of the focus group discussions.
2. Analysing how often a concept is raised as a discussion point/comment in the focus group transcript. An often-quoted concept is described as being well-grounded using the terminology from Grounded Theory. Conversely, the most poorly-grounded concepts appear in the transcripts very few times, if any more than once each.
3. Debating the ways in which the concepts can be grouped into broader themes.
4. Deciding on the relevant themes
5. Motivating for the use of theme maps (diagrammes) in the analysis
6. Introducing the generic structure of a “theme map”, with a guide as to how to interpret the diagrammes provided.
7. Identifying the key (positive/negative/neutral) associations between concepts, sub-themes and themes. The theme maps are used to assist in this analysis
8. Ranking the concepts and themes by the number of links established between them in the analysis in Step 7 above (otherwise known as density of each concept/theme in Grounded Theory).

### RESULTS OF FOCUS GROUPS A and B

**Group A participants:** Staff and community members at Madwaleni

**Group B participants:** Community members at Xora Community Health Centre

#### 1. FOCUS GROUPS A AND B (MEMBERS): IDENTIFICATION OF CONCEPTS

The following concepts were identified from the focus group discussions, listed in alphabetical order (71 concepts):

access	adherence	Advice	AIDS	Alcohol	ARVs (antiretrovirals)
bonding	Busy	caregiver	child	choice	clinical support
comfort	community perceptions	counselling	course of disease	cure	denial
dependencies	discipline	disclosure	education	elderly	employment
family	food parcel	fractured family	free of stress	grant	hand-to- mouth*

healthy	HIV	HIV wellness	home visit	hope	hunger
illness	income generation	isolation	knowledge	join and attend	lack of money
lifestyle choices	making excuses	male	marriage	member follow-up	mutual support
normality	OIs (opportunistic infections)	one-stop shop	parental control	paternal dominance	PMTCT (prevention of mother-to-child-transmission)
queue	religious faith	respect	safe sex	scary	self-respect
side effects	smoking	split SG (split support group)**	staff confidentiality	status acceptance	stigma
test	transport	virus	waiting time	white car	

**Table 5: Concepts identified from Focus Groups A and B (N=71)**

\* hand-to-mouth refers to the existence members of the local community have to eke out in the face of very low economic standards. More than just preoccupation with materialism, the phrase captures the harsh realities of surviving on the absolute minimum.

\*\* split SG (split support group) refers to the expressed preference of focus groups participants to have different support groups established for groups of people with different needs (for example, new members versus established members)

## 2. FOCUS GROUPS A AND B (MEMBERS): RANKING CONCEPTS BY GROUNDEDNESS (PREVALENCE)

The simplest way of categorising the concepts is ranking on the base of the prevalence with which the issue (concept) is raised in the focus groups (G= well/poorly grounded). More analysis is understandably devoted to those concepts and themes containing well-grounded concepts. Once all the quotations were analysed and categorized into the above concepts, the following groundedness (G) ranking was calculated:

CONCEPT	G	CONCEPT	G	CONCEPT	G
safe sex	1	hope	3	Comfort	3
religious faith	1	hunger	3	parental control	4
Caregiver	1	self-respect	3	Busy	4
Smoking	1	side-effects	3	paternalrelationship	4
staffconfidentiality	2	respect	3	dependency	4
memberfollowup	2	pmtct	3	Marriage	4

choice	2	white car	3	Cure	4
counseling	2	communityperceptions	3	onestopshop	5
homevisit	3	alcohol	3	Education	5
grant	3	clinical support	3	splitSG	5
employment	5	lack of money	10	HIV	13
making excuse	5	HIV wellness	10	knowledge	13
food parcel	5	transport	10	free of stress	14
scary	6	income generation	11	Stigma	15
virus	7	OIs	11	Bonding	15
Aids	7	disclosure	11	Illness	16
advice	7	healthy	12	Child	16
denial	7	queue	12	Normality	17
discipline	8	isolation	12	Male	18
elderly	9	course of disease	12	Family	18

CONCEPT	(G)	CONCEPT	(G)
waiting time	18	joining programme	27
hand-to-mouth	19	ARVs	53
adherence	20	mutual support	53
access	23		
accepting status	24		
test	25		

**Table 6: Concepts ranked by groundedness – Focus Group A and B**

### 3. FOCUS GROUPS A AND B (MEMBERS): MOTIVATION BEHIND GROUPING CONCEPTS INTO BROADER THEMES

Establishing some useful links between concepts enabled broader themes to be identified. It was recognized that such links were defined in different ways:

- a) Grouping concepts into broad categories mirroring a three-stage assessment of a patient in consultation: the clinical aspects concerning the HIV, disease and antiretrovirals; the individual beliefs, concerns, fears and expectations around their positive HIV status, and lastly the contextual issues faced by the patient in this community.

Clinical	illness/courseofdisease/healthy/OIs/HIVwellness/HIV/AIDS/virus/cure/pmtct/ARVs (antiretrovirals)/side-effects
Individual	support/bonding/respect/knowledge/choice/isolation/advice/discipline/education/self-



	respect/comfort/hope/acceptingstatus/test/normality/stigma/freeofstress/disclosure/denial/scary/procrastination-excuse/communityperceptions/white car/adherence/dependency
Contextual	distance/waitingtime/queue/transport/onestopshop/busy/caregiver/family/fractured family/male/child/elderly/parentalcontrol/marriage/paternaldominance/memberfollowup/homevisit/splitsupportgroup/joiningprogramme/clinicalsupport/counseling/staffconfidentiality/hand-to-mouth/incomegeneration/money/employment/foodparcel/grant/hunger/smoking/alcohol/religiousfaith/safesex/whitecar

**Table 7: Concepts grouped into themes using 3-stage assessment – Focus Groups A and B**

- b) Grouping concepts into three different broad themes concerning the psycho-social needs of the members/non-members (demand), the knowledge-based facts around HIV and the disease it causes, as well as those concepts depicting the systems within the HIV programme (supply).

Psycho-social (SERVICE DEMAND)	acceptingstatus/normality/stigma/freeofstress/disclosure/denial/scary/makingexcuses/communityawareness/support/bonding/respect/knowledge/choice/isolation/advice/discipline/education/selfrespect/comfort/hope/caregiver/family/male/child/elderly/parentalcontrol/marriage/paternaldominance/handtomouth/money/employment/dependency/hunger/religious faith
HIV-specific (SERVICE- RELATED)	HIV/AIDS/virus/cure/test smoking/alcohol/ /safe sex ARVs(antiretrovirals),adherence/sideeffects/illness/courseofdisease/healthy/OIs/HIVwellness
Programme and systems (SERVICE SUPPLY)	distance/waitingtime/queue/transport/onestopshop/busy/member followup/homevisit/splitsupportgroup/joiningprogramme/clinical support/counseling/staffconfidentiality/ pmtct/white car/foodparcel/grant/income generation

**Table 8: Concepts grouped into themes on basis of supply and demand assoc. – Focus Groups A and B**

- c) Perhaps the clearest way to highlight common themes established in the focus groups is to group together concepts as subject themes or categories; the concept that best captures the common thread to a group of concepts graduates into a theme:

<b>1. STATUS ACCEPTANCE</b> statusacceptance/normality/ stigma/freeofstress/disclosure/ denial/scary/making excuses/ communityperceptions/	<b>2. ACCESS</b> access/ transport/busy/lack of money	<b>3. MUTUAL SUPPORT</b> mutual support/bonding/respect/ knowledge/choice/isolation/ advice/discipline/education/self- respect/comfort/hope/white car
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<b>4.DEPENDENCIES</b> hand-to-mouth/income generation/employment/ foodparcel/dependency/grant/ hunger	<b>5. COURSE OF DISEASE</b> illness/courseofdisease/healthy/ OIs/HIVwellness	<b>6. FAMILY</b> caregiver/family/male/child/ elderly/parentalcontrol/marriage /paternaldominance/pmtct
<b>7. ARVS</b> ARVs(antiretrovirals)/ adherence/side-effects	<b>8. VIRUS</b> HIV/AIDS/virus/cure/test	<b>9. LIFESTYLE CHOICES</b> lifestylechoices/smoking/alcohol /religious faith/safe sex
<b>10. JOIN AND ATTEND / SYSTEMS &amp; STRUCTURE</b> memberfollowup/homevisit/split supportgroup/joiningprogramme /clinicalsupport/counseling/staff confidentiality/waiting time/queue/one-stop-shop		

**Table 9: Concepts grouped into “Ten Themes” – Focus Group A AND B**

**4. FOCUS GROUPS A AND B (MEMBERS):**     CHOICE OF THEMES

The discussion below uses this last structure above (c), highlighting those concepts in each of the TEN themes that are either preventing or facilitating member value in both joining and regularly attending the Madwaleni HIV programme. The themes, therefore, are:

1. Acceptance and understanding of HIV positive status
2. Improving access to care
3. Providing mutual support
4. Redefining dependencies
5. Awareness of the course of disease
6. Importance of the family unit
7. Impact of antiretrovirals
8. Knowing the virus
9. The right lifestyle choices
10. Encouraging joining and attendance/Best systems and structure

## 5. FOCUS GROUPS A AND B (MEMBERS): MOTIVATING FOR THE USE OF A THEME MAP

In the analysis of the transcripts, there were many associations established besides the grouping of concepts within the ten themes:

- Each concept within its theme is either positively (help), negatively (hinder), or neutrally associated with its own theme
- Some concepts are either negatively or positively associated with other themes and concepts
- Some concepts are notably not associated with other concepts and themes, against expectations concepts of different themes.

These associations are depicted pictorially below in THEME MAPS, in order to:

- Simplify and assist the discussion following in this research
- Allow for collating of the number of links associated with each concept and theme. This number is representative of the impact and influence of a particular concept; often independently of how many times the concept is raised in the focus groups. This influence of a concept is referred to its density (Grounded Theory).
- As an ongoing template to aid discussion amongst the HIV programme management staff when evaluating strategy and development of the programme

## 6. FOCUS GROUPS A AND B (MEMBERS): INTRODUCING THE GENERIC THEME MAP

A model to the structure of a THEME MAP is provided below, with an explanation following the diagramme:

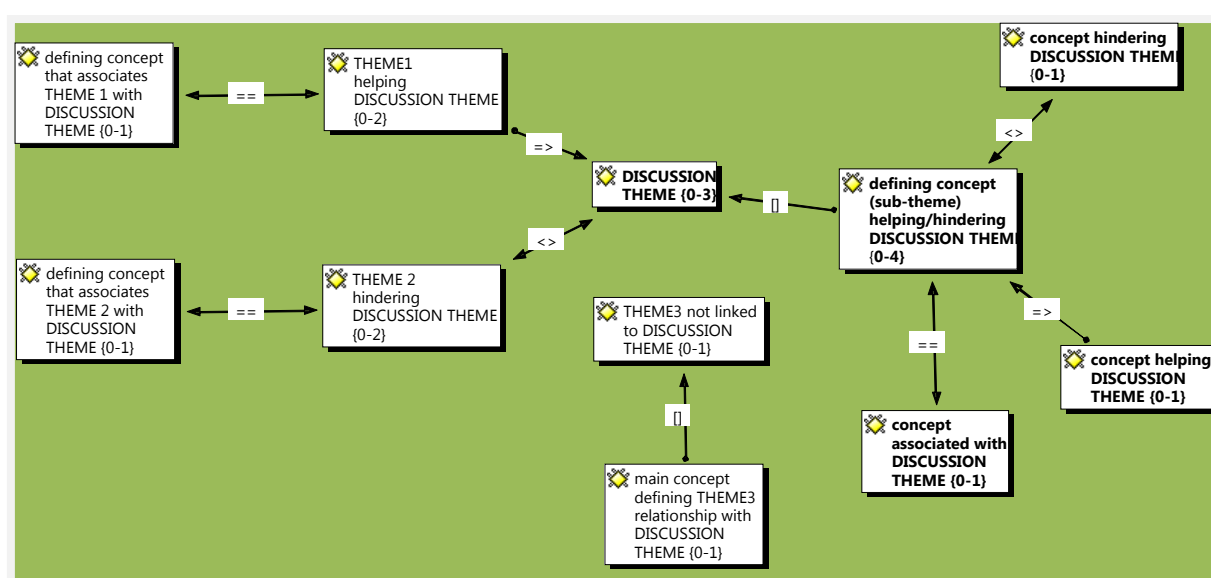


Figure 4: Generic theme map

A guide to the theme map:

1. Each diagramme is a pictorial representation of the issues raised in the focus groups under one particular theme (DISCUSSION THEME). Those **concepts** that are part of the theme under discussion are in bold.
2. There are obviously no quotations linked to the concepts and themes in this example above. The DISCUSSION THEME (0,3) therefore has a groundedness of zero, but a density of 3 for the direct links to three other concepts or themes as shown
3. Concepts are in small print, THEMES are in capitals to distinguish them from their composite concepts.
4. In any one THEME, the concept that best captures the common theme may double as the name of the theme. Virus and VIRUS both exist as concept and theme respectively.
5. Similarly, some of the DISCUSSION THEMES have a defining concept that most influences the theme in the context of the focus groups. This is referred to as a sub-theme. The REDEFINING NEGATIVE DEPENDENCIES theme is defined by the **hand-to-mouth** sub-theme. Other concepts making up the same theme (**grant, foodparcel, hunger**) are then linked through this sub-theme. Two sub-themes may exist - **disclosure** and **community perceptions**, for example, are not contradictory by definition, but are seen as the defining sub-themes of STATUS ACCEPTANCE, although for conflicting reasons in the context of the transcript analysis. There are some THEMES in which no particular sub-theme stands out.
6. A theme will have other concepts and themes (THEMES 2 and 3 above) which are also depicted diagrammatically to aid the discussion.
7. A [] sign, meaning “is a part of”, denotes a concept as part of a certain sub-theme or THEME (neutral association), as well being in bold type.  
An <> denotes “hinders”  
An arrow => depicts “is a cause of” or “helps”  
A “==” means “is associated with” and is a more tenuous link than [] or =>.

Example: The concept denial is an example of being a hindrance to its theme of STATUS ACCEPTANCE whereas the sub-theme disclosure is a help.

8. Key concepts that do not form part of the discussion theme in question – but that are positively/negatively/ neutrally associated with it – are also depicted as such in the THEME MAPS.
9. Some themes are not linked as a whole to the central theme under discussion; attention may be drawn to this fact by its presence as an isolated, un-linked theme in the map.

## 7. FOCUS GROUP A AND B (MEMBERS): ANALYSIS OF RESULTS BY INDIVIDUAL THEME

RESULTS: THEME 1. ACCEPTANCE AND UNDERSTANDING OF HIV POSITIVE STATUS

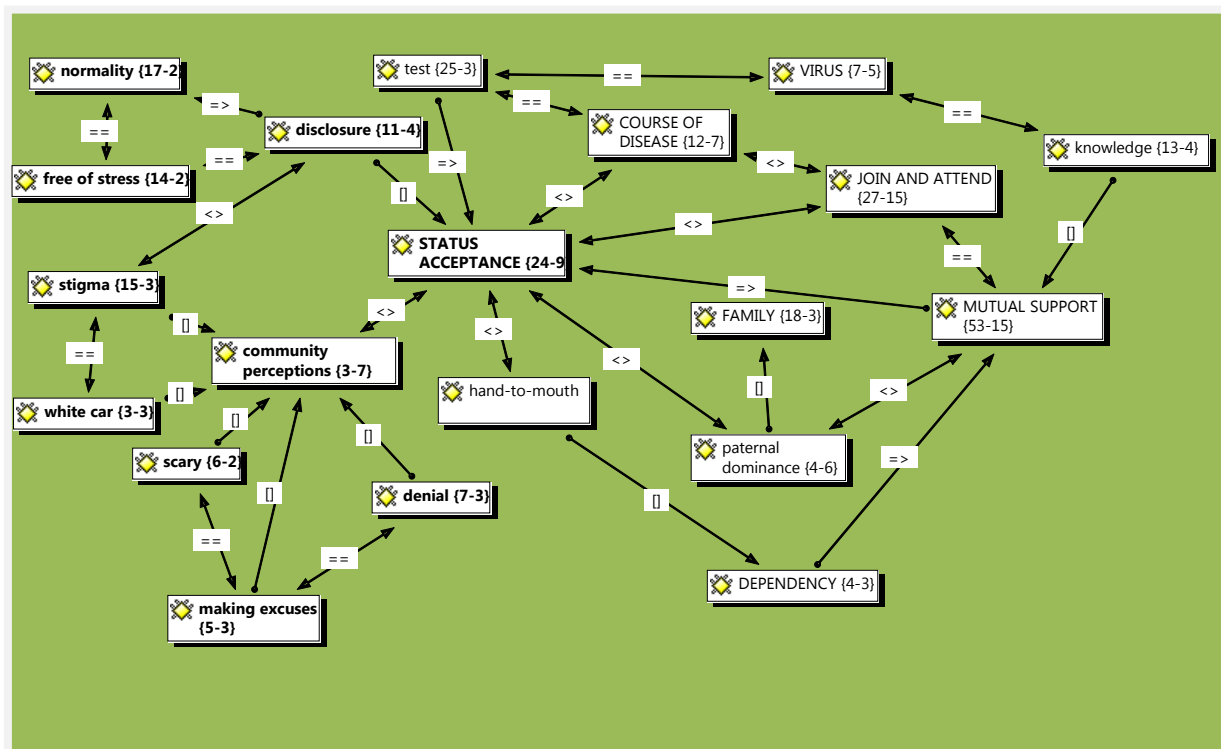


Figure 5: Focus Groups A and B Theme Map: STATUS ACCEPTANCE

The theme STATUS ACCEPTANCE is composed of the following concepts: normality, stigma, free of stress, disclosure, denial, scary, community perceptions, making excuses, status acceptance (doubles as theme) and white car

MUTUAL SUPPORT (defined as that available within the support group) helps with STATUS ACCEPTANCE.

Disclosure and community perceptions emerged as the key sub-themes within STATUS ACCEPTANCE. Each was not necessarily highly grounded but had the highest densities of concepts within the theme.

Normality (as a personal goal, and being seen as normal) emerged as the most well-grounded concept within the theme.

Knowledge gained outside of the support group (as a concept within MUTUAL SUPPORT) does not help with STATUS ACCEPTANCE, because such transfer of knowledge happens infrequently (not because it is inherently a hindrance when it does occur).

A key sub-theme to STATUS ACCEPTANCE, community perceptions is, on balance, a hindrance to STATUS ACCEPTANCE.

Paternal dominance is, as the key sub-theme of FAMILY, the main reason for family support often hindering STATUS ACCEPTANCE.

(cont...)

For a significant proportion of the members, STATUS ACCEPTANCE only happens after joining the programme.

On account of the current structure and approach presuming acceptance of status occurs before a person joins the programme, STATUS ACCEPTANCE is itself an obstacle or hindrance to JOINING THE PROGRAMME.

The hand-to-mouth concept (as the key sub-theme to DEPENDENCY) is a hindrance to STATUS ACCEPTANCE.

Test for HIV helps with initiating STATUS ACCEPTANCE but further understanding of the COURSE OF DISEASE is limited, rendering the latter theme a hindrance to improving STATUS ACCEPTANCE.

## RESULTS: THEME 2. IMPROVING ACCESS TO CARE

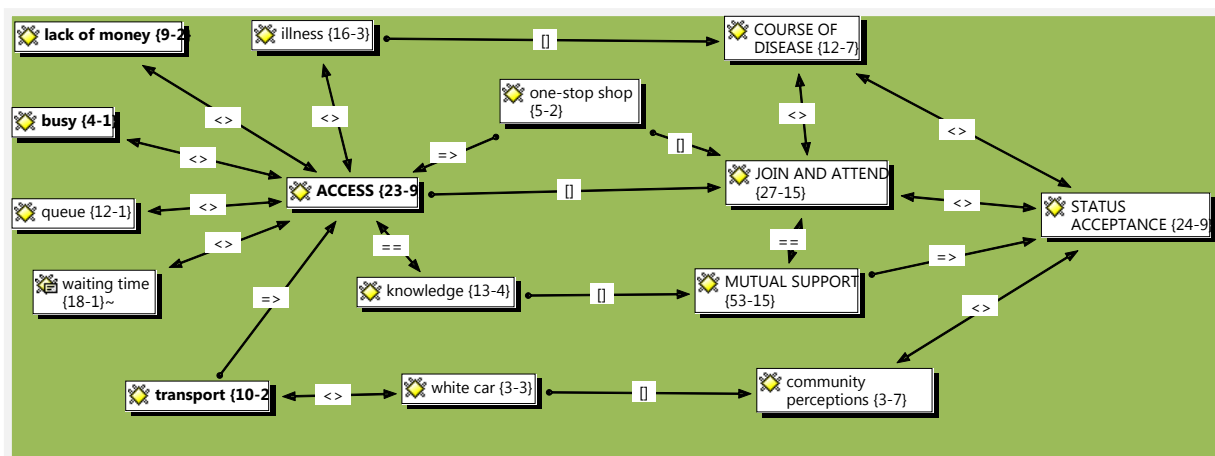


Figure 6: Focus Groups A and B Theme Map: ACCESS TO CARE

The obvious definition of access is by those concepts associated with geographical distance, namely transport, access (doubles as theme), lack of money and busy. With the exception of transport where and when available, these concepts hinder ACCESS to JOIN AND ATTEND.

Those time-related concepts once members have reached the clinic, namely busy, queues and waiting times (the latter two with high groundedness in particular) suggest significant inconvenience to many members; they hinder ACCESS to the support groups and JOIN AND ATTEND for reasons that are time-related.

Where there are practical problems around ACCESS, an illness does also not allow for easy ACCESS.

Despite the efforts at decentralizing of HIV care to primary health care clinics, problems with geographical access remain serious even at clinic level. (Total groundedness of ACCESS theme and concepts was 46, divided between Madwaleni/Group A: 6, Xora/Group B: 7 and Bomvana/pilot: 33). Differences are less significant because discussion around access was wrongly prompted by the facilitator during the pilot focus group at Bomvana. Despite this bias, the problems of geographical access even at the level of the clinic remain real. (cont...)

11 individuals in the Bomvana clinic focus group quantified the time taken to get to the clinic on foot: the average time taken was 1hr 48 minutes, and 5 participants quoted a time of 3 hrs or longer. Time delays experienced at the clinic that exacerbate ACCESS problems (part of JOIN AND ATTEND theme) appear to at least as significant at clinic level as at Madwaleni and Xora Community Health Center. (Total groundedness of queue and waiting time together is 30: Madwaleni 3, Xora 2, and Bomvana 25. Again no comparison can be drawn, rather it is noted that the issue is raised as significant at primary health care level (PHC).

Knowledge around living with HIV contributes to MUTUAL SUPPORT only once an individual has joined the programme. It is, therefore, not the motivational help to JOIN AND ATTEND that is required in the face of difficult ACCESS. It does, however, help with ongoing attendance by those who can ACCESS the programme readily.

Supportive community perceptions are also not at the critical level required to help with individual motivation to overcome ACCESS problems.

ACCESS would be improved by the attraction of the programme as a one-stop shop, but the latter is not as grounded a concept as would be required to motivate overcoming well-grounded concepts as queue, waiting time and transport.

## RESULTS: THEME 3. PROVIDING MUTUAL SUPPORT

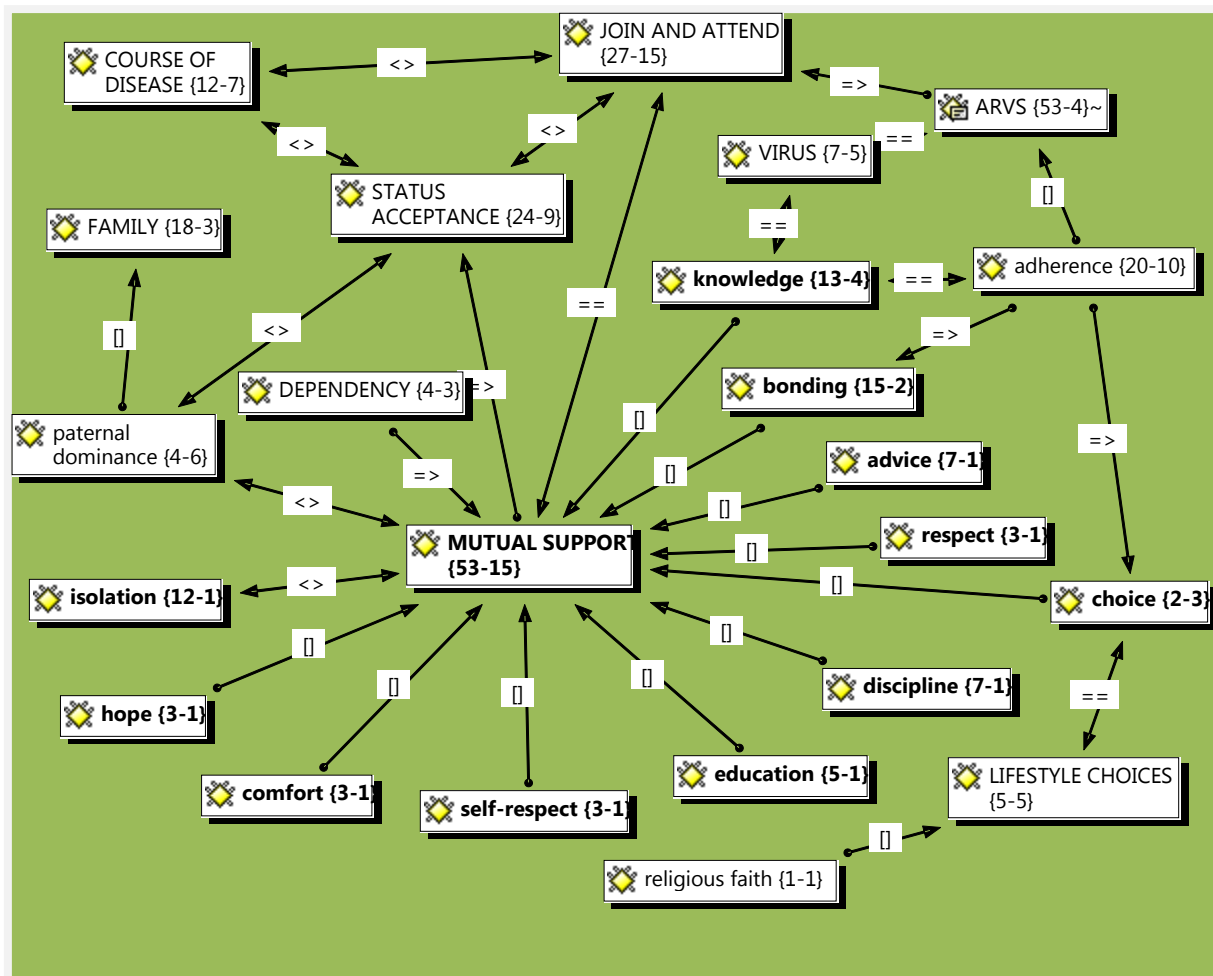


Figure 7: Focus Groups A and B Theme Map: MUTUAL SUPPORT

The concepts that are part of the MUTUAL SUPPORT theme (positively associated) are knowledge, bonding, choice, hope, comfort, self-respect, mutual support (doubles as theme), education, discipline, respect and advice. Isolation is also part of the theme, although is negatively associated with the support.

MUTUAL SUPPORT is the most grounded of concepts and themes (equal with ARVS) in the focus group transcripts.

MUTUAL SUPPORT is perceived by members as being provided within the support group, rather than being part of any larger community or family support.

Paternal dominance (high density) and fractured families, as key themes to FAMILY, are often a hindrance to support outside of the HIV programme.

Bonding is the most well-grounded of positively associated codes in the MUTUAL SUPPORT theme.

DEPENDENCY (whether negative or positive) is a help to building MUTUAL SUPPORT within the groups. Everyone is affected by the difficulties in accepting an HIV positive status, and bond together because of this common challenge. Similarly there is a bonding effect of adverse external environmental factors (lack of money, access problems, unemployment) that helps to build a common identity.

Adherence (well-grounded, high density) to the antiretrovirals is a binding force in the MUTUAL SUPPORT provided within support groups

MUTUAL SUPPORT is a key help to STATUS ACCEPTANCE for members attending the support groups

Knowledge helps with MUTUAL SUPPORT when a member of the support group, but empowering non-members with the knowledge to JOIN AND ATTEND is less common, except regarding the ARVs themselves. Knowledge and awareness of these medicines assists in motivating to join the programme, and in bonding support group members

MUTUAL SUPPORT is described with reference to the inter-member support; little mention is made of the involvement of peer educators as facilitators of that support. Their different and useful role as educators is, however, acknowledged.

No mention of any one-on-one personal support to (HIV) staff members is made by the GROUP A participants (some of whom are HIV positive programme staff).

MUTUAL SUPPORT is a help to JOINING AND ATTEND in so far as the positive effects of internal support (within support group) impact repeat attendance, but the impact on external (non-members) motivation to join is obviously indirect and therefore limited. The link is, therefore, depicted as a neutral association.

Religious faith influences an individual's motivation for choice with respect to lifestyle, but is not depicted in the transcripts as a significant basis for MUTUAL SUPPORT, despite its obvious impact and help as a cohesive force in the community. It does not, therefore, help with efforts to encourage people to JOIN AND ATTEND.



## RESULTS: THEME 4. REDEFINING DEPENDENCIES

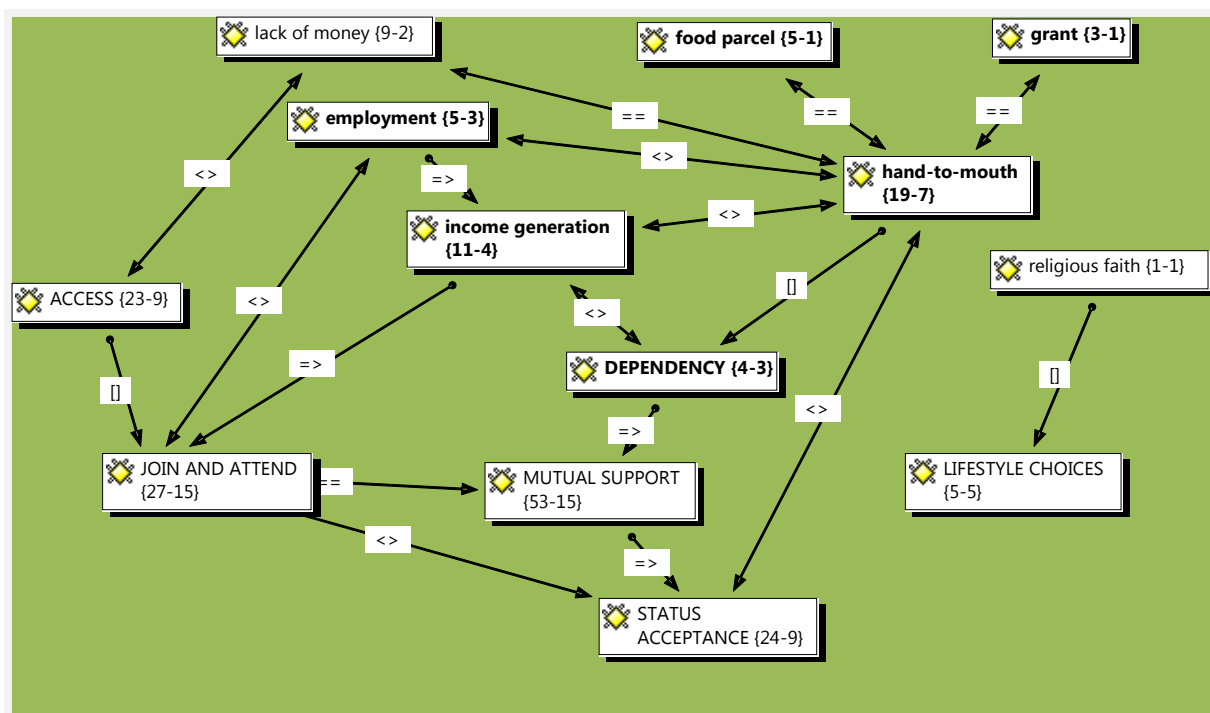


Figure 8: Focus Groups A and B Theme Map: DEPENDENCY

The concepts that are part of the DEPENDENCY theme are food parcel, hand-to-mouth, grant, income generation, employment, and dependency (doubles as theme).

DEPENDENCIES are of two kinds, as emerging from the transcripts: negative and positive dependencies.

Hand-to-mouth concept (well-grounded), as the key sub-theme to DEPENDENCY, hinders the redefining of negative dependencies.

Income-generation (poorly grounded), while it could help break the hand-to-mouth reliance, is not part of the programme. It is, therefore, not helping to people to JOIN AND ATTEND, nor is the practice helping to redefine negative dependencies in to more sustainable development initiatives

Employment (poorly grounded) does help to counter negative DEPENDENCY.

Lack of money contributes to DEPENDENCY and is a key hindrance to ACCESS TO CARE and JOINING AND ATTENDING.

DEPENDENCY is, on balance, only helping with STATUS ACCEPTANCE for its constructive dependency on the bonding as part of the MUTUAL SUPPORT provided by the support groups

Religious faith is not depicted in the transcripts as a significant contributor to DEPENDENCY, either positive or negative.

## RESULTS: THEME 5. AWARENESS OF THE COURSE OF DISEASE

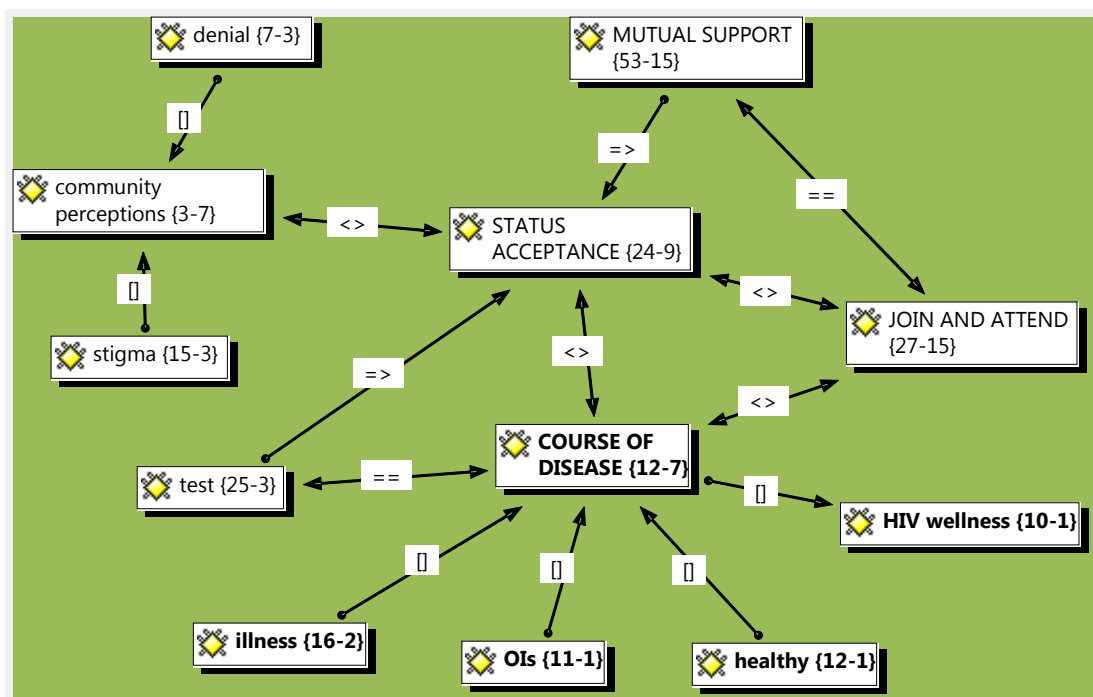


Figure 9: Focus Groups A and B Theme Map: COURSE OF DISEASE

The concepts that are part of the COURSE OF DISEASE theme are illness, healthy, OIs (opportunistic infections), course of disease (doubles as theme) and HIV Wellness.

Each of HIV Wellness, OIs, illness and healthy are moderately well-grounded concepts (10, 11, 12, 16 respectively). Of the quotations related to HIV Wellness, the context in which the concept is raised is understandably predominantly health and prevention (high overlap with healthy), but OIs and illness are contextualized predominantly around problems with treatment (and access to treatment/care) rather than HIV Wellness. Problems with ACCESS do not help with gaining an understanding of HIV Wellness and COURSE OF DISEASE.

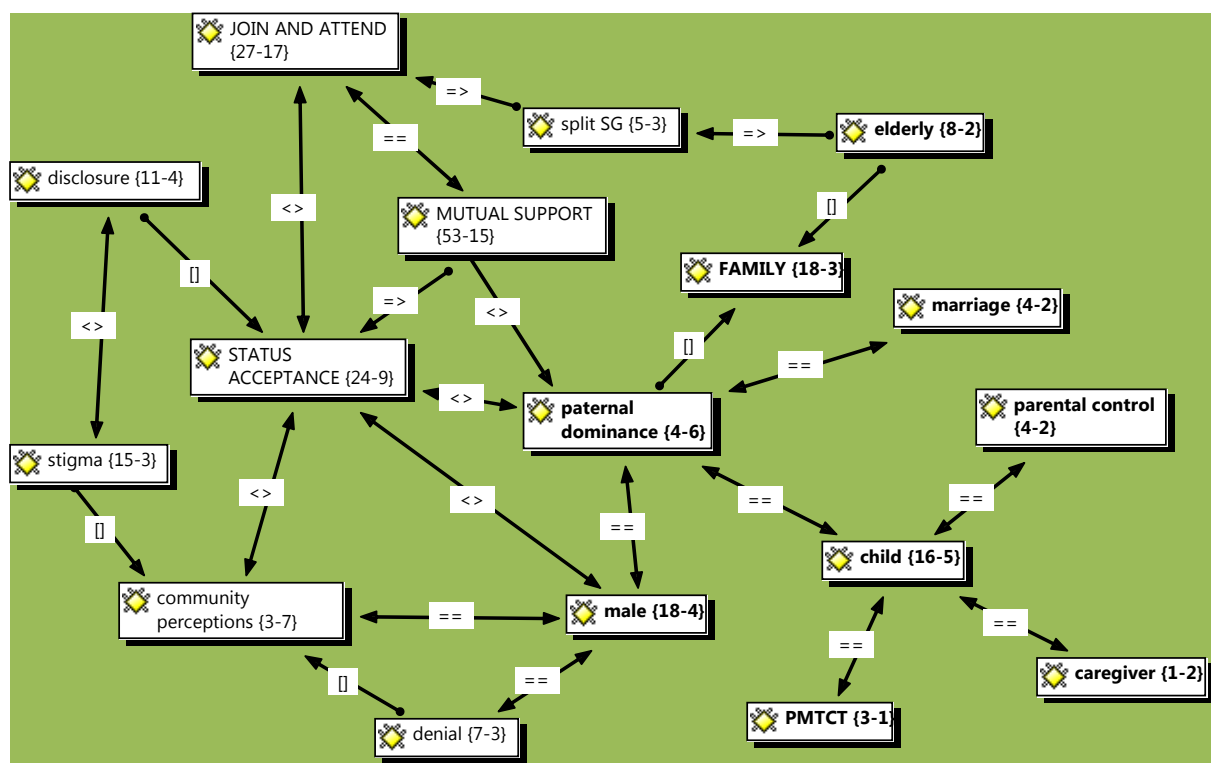
Pre-occupation with the HIV test itself (well-grounded), and STATUS ACCEPTANCE, hinders development of an awareness of the COURSE OF THE DISEASE. For this reason, test falls more easily in the KNOWING THE VIRUS theme, as opposed to COURSE OF DISEASE.

HIV wellness is a key sub-theme of COURSE OF DISEASE. A low-density concept, HIV wellness is notable for its lack of positive association with many of the other themes.

A poor understanding of HIV Wellness and the COURSE OF DISEASE renders the same as fairly ineffective as a motivator to JOIN AND ATTEND early in the course of disease.

Considering the poor link in the support group setting, community perceptions is not linked to the COURSE OF DISEASE. The former does not, therefore, help with motivation to JOIN AND ATTEND the programme.

RESULTS: THEME 6. THE IMPORTANCE OF THE FAMILY UNIT



**Figure 10: Focus Groups A and B Theme Map: FAMILY**

The concepts of male, child, caregiver, parental control, paternal dominance, family (doubles as theme), marriage, elderly, and PMTCT make up the FAMILY theme

Paternal dominance is widely prevalent within the family and community structures, and hinders development of a strong FAMILY unit.

Male gender is a hindrance to JOIN & ATTEND the programme

Male reluctance to JOIN AND ATTEND is fuelled by both stigma around HIV and denial of status. The transcripts did not reveal which of these hindrances dominates, although the stigma concept is he more grounded.

It is largely because of the influence of male reticence that community perceptions is seen, on balance, as a hindrance to STATUS ACCEPTANCE preceding JOIN AND ATTEND.

It is not clear whether more women than men are helped for their societal and family role to JOIN AND ATTEND without a full STATUS ACCEPTANCE, but there is enough evidence to suggest the question be more adequately researched.

Child(ren) are a concern to the caregivers (moderate density), and opinions suggest they are not adequately prioritized in the programme structure to ensure both more children and adults JOIN AND ATTEND

Fractured families was not chosen as a concept because there was no mention made by participants of either absent adults or orphaned and/or neglected children. It is not clear why these issues were not raised, as logic suggests a fractured family to be a powerfully disruptive force in hindering individuals to JOIN AND ATTEND the programme. (cont.)

The elderly contribute a dynamic that supports the proposal of splitting the support group into smaller groups (split SG) in the interests of helping more people persuaded to JOIN AND ATTEND

The transcripts suggest that marriage is a hindrance for women to JOIN AND ATTEND, and conversely, the normally reticent man will have the additional (but submissive) partner input as a help to JOIN AND ATTEND the programme

PMTCT is not a well-grounded concept partly for the exclusion of pregnant women in the support group as they are rushed on to the programme.

## RESULTS: THEME 7. IMPACT OF ANTIRETROVIRALS

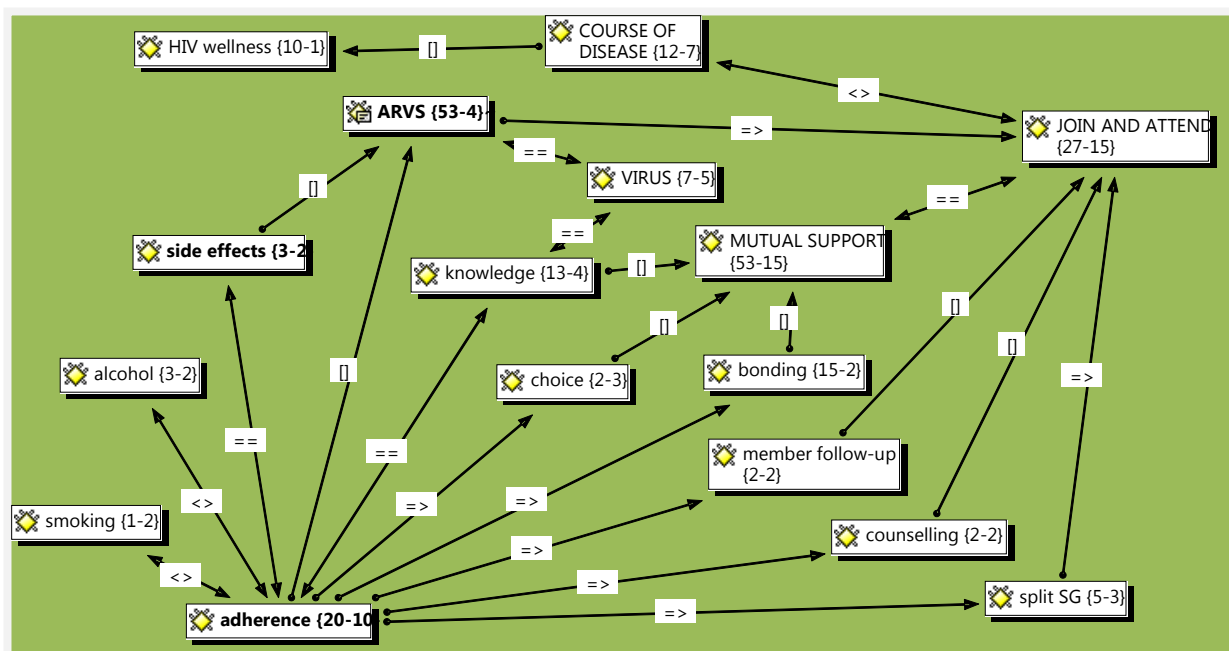


Figure 11: Focus Groups A and B Theme Map: ARVS

The concepts that are part of the ARVS theme are adherence, ARVs (doubles as theme) and side-effects,

ARVS was one of the most grounded of all the concepts and themes, equal to second only to MUTUAL SUPPORT.

The key sub-theme of ARVS is adherence. As a concept, adherence had one of the higher groundedness and densities in combination. It is singled out as a dominant topic of discussion within the focus groups.

Adherence to ARVS forms the main topic maintaining the strength of MUTUAL SUPPORT within the support groups

The knowledge concept, a vital part of the MUTUAL SUPPORT, centers predominantly around the topics of ARVs and adherence.

This focus on ARVS and adherence drives the motivation to JOIN AND ATTEND the programme.

(cont...)

Participants felt that learning around the topic of adherence to ARVs had an end-point; increase in knowledge around this topic was therefore limited. The discussion around the possible splitting of the support group (split SG) stemmed from recognition of the different needs of members, ranging from new to veteran members.

Of particular note, is the lack of obvious association of ARVS with HIV Wellness. Not a single quote was categorised for the ARV and HIV Wellness concepts together.

Side-effects is a poorly grounded concept not referenced to any significant degree in the focus group discussions

Adherence does neatly influence the motivation to adopt the right LIFESTYLE CHOICES for its valid claim to a place as a concept within the LIFESTYLE CHOICES itself.

JOIN & ATTEND is helped by member follow-up, but this follow-up (by programme staff) is specifically of patients taking ARV treatment, whether doing so poorly or not at all.

JOIN AND ATTEND is associated with the concept adherence through concepts representing system elements of the programme, namely member follow-up, split support group (split SG), and counseling

## RESULTS: THEME 8. KNOWING THE VIRUS

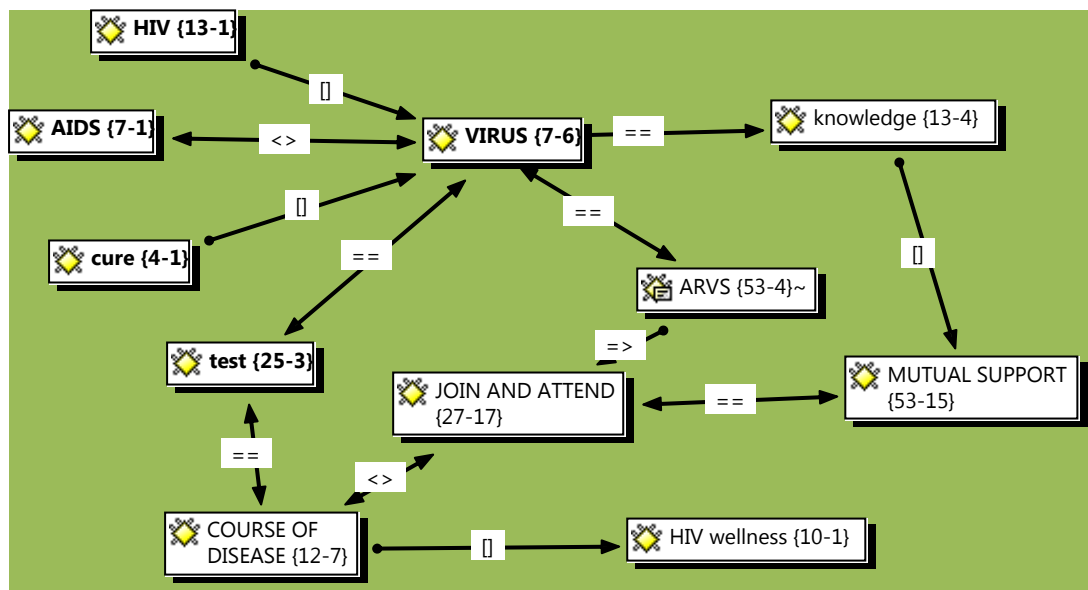


Figure 12: Focus Groups A and B Theme Map: VIRUS

The concepts HIV, test and AIDS, virus (doubles as theme) and cure are logically included under the VIRUS theme.

The virus concept covers those quotations referencing the virus as a living entity. It is not particularly well-grounded. Even in combination with the references to HIV as an entity in general, the two do not stand out for their combined prevalence in the transcripts.

AIDS is negatively associated with the VIRUS theme for the inaccurate reference to AIDS more often as a virus rather than a clinical syndrome.

(cont.)



RESULTS:      THEME 10.      ENCOURAGING JOINING AND ATTENDANCE / BEST SYSTEMS  
AND STRUCTURES

The concepts that are part of the JOIN AND ATTEND theme are member follow-up, home visit, split SG (support group), joining programme (doubles as theme), clinical support, counseling, staff confidentiality, waiting time, queue, and one-stop-shop.

Noting that these concepts reflect elements of the programme service that were highlighted in the focus groups, the results relating to analysis of THEME 10: ENCOURAGING JOINING AND ATTENDANCE are divided into two sub-sections:

1. The specific associations between the concepts that are part of the JOIN AND ATTEND theme and other key concepts and their themes, in keeping with the results analyses of the other nine themes. This therefore provides a qualitative analysis of the fit between the service and the perspectives/experiences of the members.
2. The associations of the themes and sub-themes with the general theme of JOINING AND ATTENDING excluding the latter theme's specific concepts, so highlighting influence; how the perspectives/experiences of the members help or hinder HIV positive individuals to join and attend the programme (positive, negative or neutral associations).

1.

The concepts that are part of the JOIN AND ATTEND theme are member follow-up, home visit, split SG (support group), joining programme (doubles as theme), clinical support, counseling, staff confidentiality, waiting time, queue, and one-stop-shop.

Waiting time and queue are both time-related concepts that are part of the JOIN AND ATTEND theme; these concepts are a hindrance (highly grounded) to members wishing to JOIN AND ATTEND.

Clinical support is a poorly grounded concept, as there are few quotes relating to the specific assistance provided by either nurses or doctors. It is however associated with illness, HIV Wellness and healthy, which collectively contributed were well-grounded at 38 in total.

To the extent that the one-stop-shop (accessing different HIV Wellness services during one visit) is a help to JOIN AND ATTEND, it is not a well-grounded concept, suggesting this factor does not contribute a measure of success in an evaluation of the programme systems in place.

Member follow-up is acknowledged as being related to adherence problems: members who do not collect their ARVs are proactively sought, rather than following up those who do not attend support group.

The stigma attached to the white car – an HIV programme car known to the community – undermines the supportive intention of the staff in conducting a home visit. On balance, however, the home visit is perceived as a useful and appreciated service by members.

Participants felt there could be advantages to a split SG (support group); the distinction in groups to be made around issues of adherence to ARVs, as well as time on ARVs.

Staff confidentiality was a poorly grounded concept, possibly for reasons none of the focus group participants were health care workers.

Counseling refers to the individual counselling given by lay counselors, nurses or doctors; it is a poorly grounded concept, as opposed to MUTUAL SUPPORT.

## 2.

STATUS ACCEPTANCE is itself a hindrance to JOIN AND ATTEND as the programme is currently structured. The HIV test is the initial driver towards STATUS ACCEPTANCE, and there is initial encouragement to JOIN AND ATTEND.

ACCESS as defined by the concepts related to geographical distance, manifesting especially in the problems with transport, is a hindrance to JOIN AND ATTEND.

MUTUAL SUPPORT is a help to JOIN AND ATTEND in so far as the positive effects of internal knowledge and bonding (within support group) impact repeat attendance, but the impact on external (non-members) motivation to join is obviously indirect and therefore limited. The association is, therefore neutral on balance.

The key sub-theme of DEPENDENCY is hand-to-mouth, which has its most significant (negative) association with STATUS ACCEPTANCE, over MUTUAL SUPPORT (positive). DEPENDENCY is associated indirectly with JOIN AND ATTEND through its links to MUTUAL SUPPORT. Both negative and positive dependencies help with MUTUAL SUPPORT within the programme, but DEPENDENCY is then follows the lead of MUTUAL SUPPORT for its effect on JOIN AND ATTEND (neutral).

HIV Wellness is the key sub-theme of COURSE OF DISEASE but its prominence is muted for the focus on reacting to illness. The understanding of the importance of HIV Wellness and COURSE OF DISEASE is, therefore, ineffective as a motivator to JOIN AND ATTEND.

While many of the concepts making up the FAMILY theme are hindrances in a person's potential to JOIN AND ATTEND, namely marriage (negative association for females, positive for males), paternal dominance remains the key sub-theme of FAMILY that suggests, on balance, a negative association with JOIN and ATTEND.

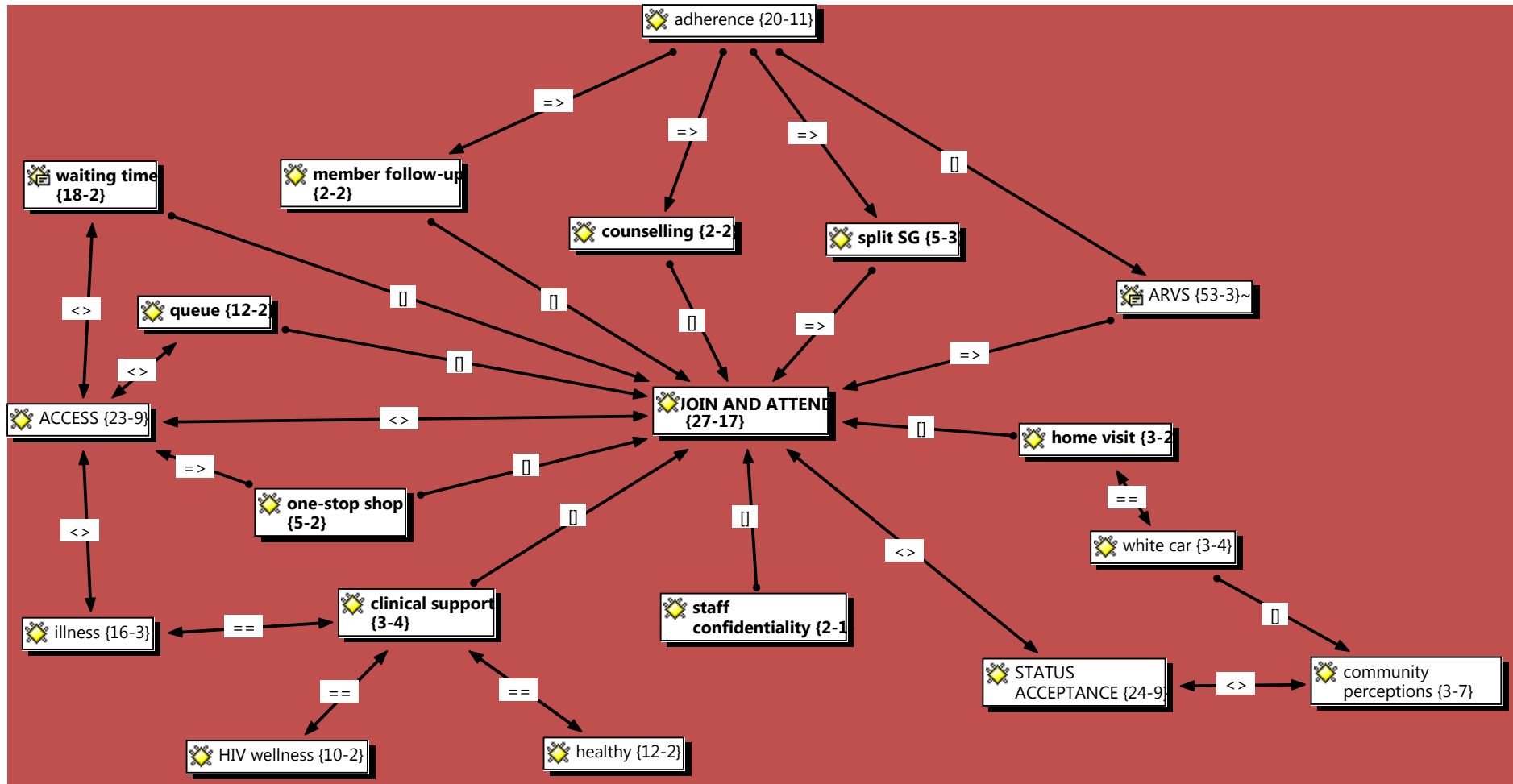
A strong focus on ARVS and its key sub-theme adherence drives the motivation to JOIN AND ATTEND the programme, even before STATUS ACCEPTANCE has occurred.

For the apparent poor impact of HIV Wellness and the COURSE OF DISEASE, and the confusion between the HIV virus and the clinical syndrome of AIDS, the VIRUS theme is a help to motivating people to JOIN AND ATTEND only in so far as its positive association with ARVS improves the latter's impact on people's motivation.

For being poorly grounded as a theme in the focus group, there is no clear evidence that LIFESTYLE CHOICES are a help or hindrance in an individual's decision to JOIN AND ATTEND.

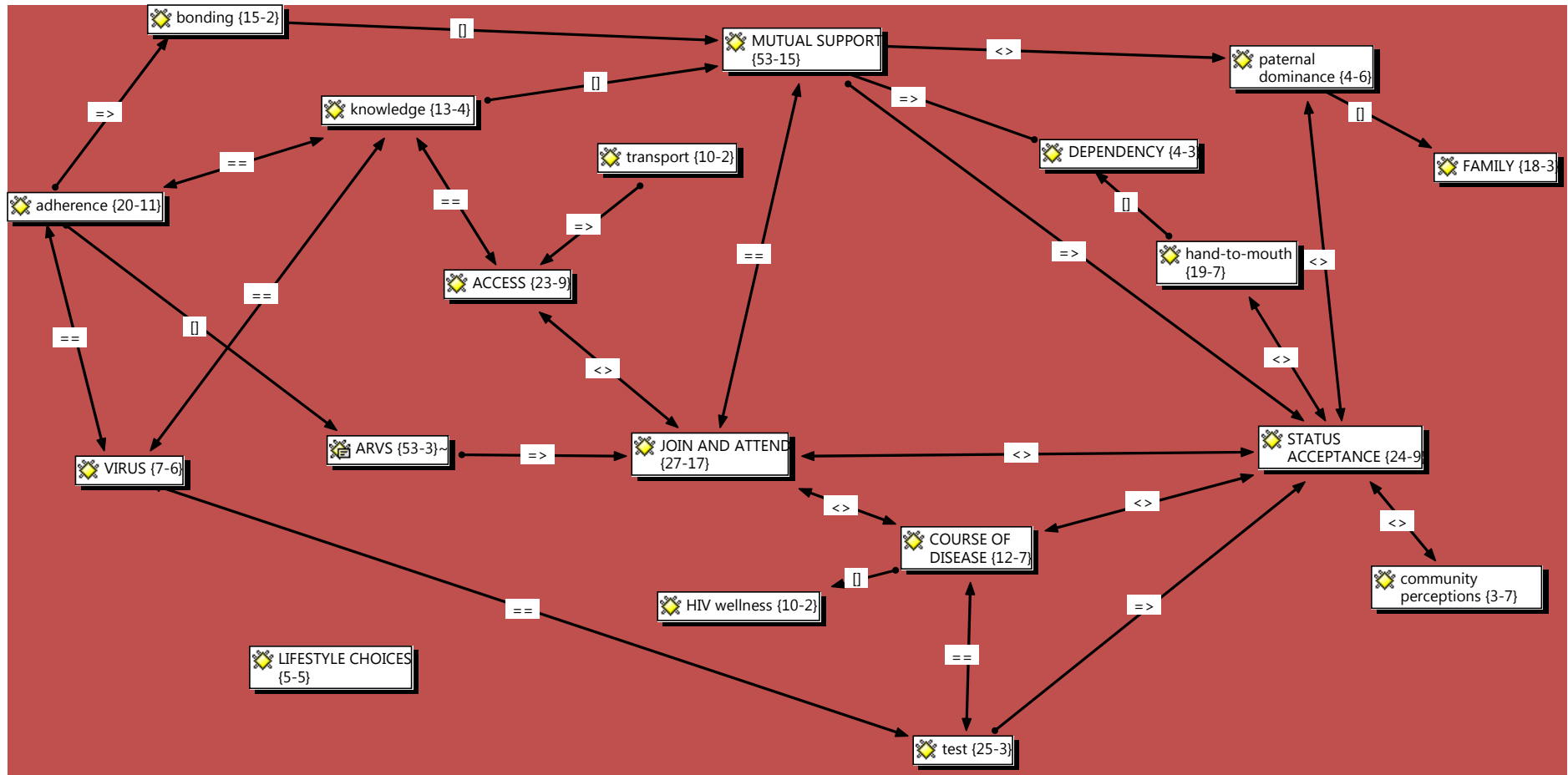


1.



**Figure 14: Focus Groups A and B Theme Map: JOIN AND ATTEND (Results sub-section 1)**

2.



**Figure 15: Focus Groups A and B Theme Map: JOIN AND ATTEND (Results sub-section 2: Associations between themes/sub-themes and JOIN AND ATTEND)**

**8. FOCUS GROUPS A AND B (MEMBERS):**     **RANKING CONCEPTS AND THEMES BY NUMBER OF ASSOCIATIONS (DENSITY)**

It is now useful to rank all the original concepts (no = 71) with respect to their density (D); that is the number of links with other codes and themes as resulted from the links established in the diagrammes above:

CONCEPT	G	D	CONCEPT	G	D
mutual support	53	15	elderly	8	2
join and attend	27	15	scary	6	2
adherence	20	11	one-stop shop	5	2
status acceptance	24	9	parental control	4	2
access	23	9	marriage	4	2
hand-to-mouth	19	7	side effects	3	2
course of disease	12	7	alcohol	3	2
community perceptions	3	7	counseling	2	2
child	16	6	member follow-up	2	2
virus	7	6	smoking	1	2
paternal dominance	4	6	waiting time	18	1
lifestyle choices	5	5	HIV	13	1
male	18	4	queue	12	1
knowledge	13	4	isolation	12	1
income generation	11	4	OIs	11	1
disclosure	11	4	AIDS	7	1
ARVs	53	3	discipline	7	1
test	25	3	advice	7	1
family	18	3	food parcel	5	1
illness	16	3	busy	4	1
stigma	15	3	education	5	1
denial	7	3	cure	4	1
employment	5	3	respect	3	1
split SG	5	3	hope	3	1
making excuses	5	3	comfort	3	1
dependencies	4	3	grant	3	1
white car	3	3	home visit	3	1
choice	2	3	PMTCT	3	1
normality	17	2	clinical support	3	1
bonding	15	2	self-respect	3	1
free of stress	14	2	staff confidentiality	2	1
healthy	12	2	safe sex	1	1

transport	10	2	religious faith	1	1
HIV wellness	10	2	caregiver	1	1
lack of money	9	2			

**Table 10: Concepts ranked by density – Focus groups A and B**

In noting the more highly dense concepts, it is worth remembering that those original concepts that were chosen as themes and sub-themes have increased number of links (higher density). Excluding, for the moment, those concepts with a density of 2 or less, and noting the THEMES in capitals, a pattern between high density and the themes/sub-themes emerges:

CONCEPT/THEME	G	D	THEME /SUB-THEME
MUTUAL SUPPORT	53	15	THEME 3
JOIN AND ATTEND	27	15	THEME 10
adherence	20	11	=>dominant sub-theme of ANTIRETROVIRALS
STATUS ACCEPTANCE	24	9	THEME 1
ACCESS	23	9	THEME 2
hand-to-mouth	19	7	=>dominant sub-theme of DEPENDENCIES
COURSE OF DISEASE	12	7	THEME 5
community perceptions	3	7	=>dominant sub-theme of STATUS ACCEPTANCE
paternal dominance	4	6	=>dominant sub-theme of FAMILY
VIRUS	7	6	THEME 8
child	16	5	
LIFESTYLE CHOICES	5	5	THEME 9
male	18	4	
knowledge	13	4	=>dominant sub-theme of MUTUAL SUPPORT
income generation	11	4	
disclosure	11	4	
ARVS	53	3	THEME 7
test	25	3	=>dominant sub-theme of VIRUS
FAMILY	18	3	THEME 6
stigma	15	3	
denial	7	3	
employment	5	3	
split SG	5	3	
making excuses	5	3	
DEPENDENCIES	4	3	THEME 4
white car	3	3	
choice	2	3	

**Table 11: Association between density of concepts with choice of themes/sub-themes - Focus Group A and B**

## RESULTS FROM GROUPS C AND D

**Group C: HIV positive individuals who have not joined the programme (individual interviews)**

**Group D: members who attend infrequently (focus group)**

### 1. INTERVIEWS C AND D: (NON-/INFREQUENT MEMBERS): IDENTIFICATION OF CONCEPTS

The following concepts were identified from the individual C interviews (5 interviews) and the focus group D participants (7 in number), listed in alphabetical order (48 concepts):

adherence	course of disease	HIV Wellness	marriage	Queue	unsure of options
AIDS	date of grant	hope	MDRTB*	scary	waiting time
alcohol	denial	illness	misconceptions	side-effects	white car
busy	distance	knowledge	not ready	status acceptance	
caregiver	employment	lack of money	not sick	stigma	
children	family	lifestyle choices	OIs**	temporary living	
communication problems	fractured family	living away	paternal dominance	test	
concurrent meds	hand-to-mouth	making excuse	pills burden	time-consuming	
contraceptive	HIV	male	pregnant	transport	

**Table 12: Concepts identified from transcripts - Groups C and D (N=48)**

\*MDRTB multi-drug-resistant tuberculosis

\*\*OIs opportunistic infections

### 2. INTERVIEWS GROUP C AND D: (NON-/INFREQUENT MEMBERS): RANKING CONCEPTS BY GROUNDEDNESS (PREVALENCE)

The simplest way of categorising the concepts is ranking on the base of the prevalence with which the issue (concept) is raised in the focus groups (G= well/poorly grounded). In addition, the frequency with which a particular concept is linked to another (in whichever except arbitrary way) is useful for analysis purposes (D= density).

More analysis is understandably devoted to those concepts and themes containing well-grounded concepts and/or those concepts/themes that have a high density. Once all the quotations were

analysed and categorized into the above concepts, the following groundedness (G) ranking was calculated:

CONCEPT	(G)	CONCEPT	(G)	CONCEPT	(G)
distance	26	lack of money	7	misconceptions	4
transport	20	time-consuming	6	paternal dominance	4
fractured family	14	caregiver	6	adherence	4
busy	14	ARVs	6	hand-to-mouth	3
communication problems	13	unsure of options	5	family	3
waiting time	11	side-effects	5	pregnant	2
male	11	OIs (opportunistic infections)	5	living away	2
stigma	10	not ready	5	lifestyle choices	2
queue	10	employment	5	knowledge	2
HIV	10	date of grant	5	course of disease	2
test	9	children	5	concurrent meds	2
status acceptance	9	white car	4	pills burden	1
making excuse	8	temporary living	4	hope	1
denial	8	scary	4	HIV wellness	1
not sick	7	MDRTB	4	contraceptive	1
marriage	7	illness	4	alcohol	1

**Table 13: Concepts ranked by groundedness – Groups C and D**

### 3. INTERVIEWS GROUP C AND D: (NON-/INFREQUENT MEMBERS): MOTIVATION BEHIND GROUPING CONCEPTS INTO BROADER THEMES

Given the same topic was discussed in each of the focus groups, it stands to reason that there should be similar concepts identified in the each of the transcripts, irrespective of focus group. The “common ground” that participants of groups A,B,C and D share as community members further enforces these similarities, at the expense of the chiefs (Group E) who are apart for their place as non-members and community leaders.

It is therefore logical that the choice of themes for groups C and D should, for the best part, mirror the ten themes of the focus groups A and B with some important differences. No theme of MUTUAL SUPPORT and DEPENDENCIES are identified, since these are both defined with reference to the support group. The reference for participants of Groups C and D is outside the programme as non-/infrequent attendees. Some of the group D (infrequent attendees) are on ARVs and make reference to them in the transcripts, so this is included in the themes. The concepts (and groundedness) emphasise practical problems with JOIN AND ATTEND, so the LOGISTICS theme is also chosen in

addition to the ACCESS theme. JOIN AND ATTEND is not chosen as a theme in group C and D; it does, however form a crucial part of the analysis and discussion

<b>ACCESS</b> distance(doubles as theme)/transport/livingawayfrom Mbashe/temporaryliving in Mbashe	<b>FAMILY</b> fracturedfamily/marriage/male/paternal dominance/children/caregiver/family(doubles as theme)
<b>STATUS ACCEPTANCE</b> test/acceptingstatus (doubles as theme)/knowledge/	<b>COURSE OF DISEASE</b> course of disease/HIV/HIV Wellness/illness
<b>LOGISTICS</b> busy(doubles as theme)/date of grant/lackofmoney/timeconsuming/hand-to- mouth/waitingtime/queue/employment	<b>MISCONCEPTIONS</b> communication problems/misconceptions (doubles as theme)/contraceptive/OIs/ MDRTB/unsureofoptions/pregnant
<b>DENIALISM</b> notsick/stigma/denial(doubles as theme)/scary/hope/makingexcuse/whitecar/notready	<b>ARVS</b> concurrentmeds/ARVs(doubles as theme)/pillburden/adherence/sideeffects/lifestyle choices/alcohol

**Table 14: Concepts grouped into themes – Groups C and D**

4. INTERVIEWS GROUP C AND D (NON-/INFREQUENT MEMBERS):  
CHOICE OF THEMES

The discussion below uses the above grouping of concepts into themes, highlighting those concepts in each of the EIGHT themes that are either preventing or facilitating member value in both joining and regularly attending the Madwaleni HIV programme. The themes are:

1. Acceptance and understanding of HIV positive status
2. Improving access to care
3. Awareness of the course of disease
4. Importance of the family unit
5. Difficulty with logistics
6. The danger of misconceptions
7. Denialism around HIV
8. Wary of ARVs

5. INTERVIEWS GROUP C AND D (NON-/INFREQUENT MEMBERS):  
MOTIVATING FOR THE USE OF A THEME MAP

In the analysis of the transcripts, there were many associations established besides the grouping of concepts:

- Each concept within its theme is either positively (help), negatively (hinder), or neutrally associated with its own theme
- Some concepts are either negatively or positively associated with other themes and concepts
- Some concepts are notably not associated with other concepts and themes, against expectations concepts of different themes.

These associations are depicted pictorially below in THEME MAPS, in order to:

- Simplify and assist the discussion following in this research
- Allow for collating of the number of links associated with each concept and theme. This number is representative of the impact and influence of a particular concept, often independently of how many times the concept is raised in the focus groups. This influence of a concept is referred to its density (Grounded Theory).
- As an ongoing template to aid discussion amongst the HIV programme management staff when evaluating strategy and development of the programme

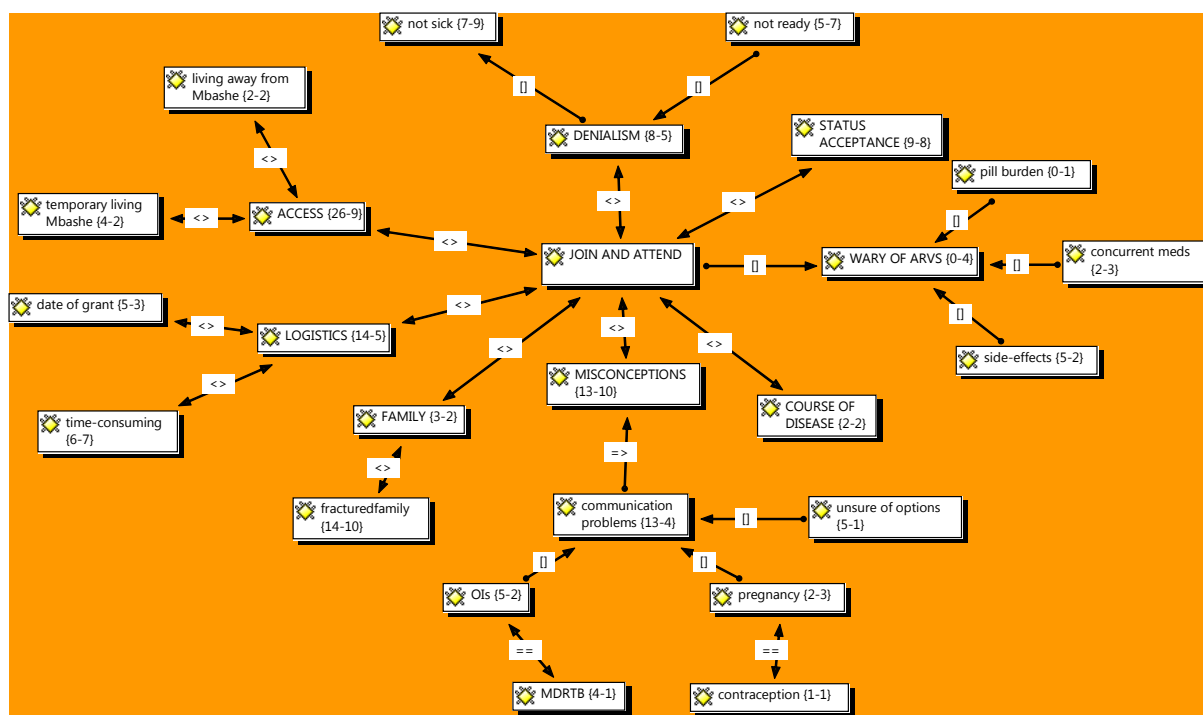
6. INTERVIEWS GROUP C AND D: (NON-/INFREQUENT MEMBERS):  
INTRODUCING THE GENERIC OF A THEME MAP

The explanation of the use of the theme map (Figure 4.) is given on page 49, and is applicable to analysis of focus groups C and D, as for the other focus groups.

7. INTERVIEWS GROUP C AND D (NON-/INFREQUENT MEMBERS):  
ANALYSIS OF RESULTS BY THEME

Given the considerable overlap between the concepts raised in these groups and other focus group participants, these results are presented for the **new** information that is evident on analysis of the transcripts. In the interests of brevity, one theme map is presented to aid the analysis and discussion.





**Figure 16: Focus Groups C and D Theme Map: JOIN AND ATTEND (Additional concepts to groups A&B)**

Fractured family is the main reason why the FAMILY theme does not, on balance, help have individuals JOIN AND ATTEND in groups C and D.

Additional LOGISTICS that hinder JOIN AND ATTEND include traveling restricted to days soon after the monthly date of grant payment , as well as individuals finding attendance time-consuming irrespective of how busy they are.

Incorrect and/or misinterpretation of education and counselling messages are an important part of the growth of MISCONCEPTIONS among non-members and infrequent attendees.

The ease with which the rationale of not ready or not ill (especially the former) can be quoted helps perpetuate specific DENIALISM which grossly hinders JOIN AND ATTEND.

ACCESS problems are complicated by a migrant component to the local community. Temporarily living in Mbashe - as well as living far from Mbashe - hinder individuals from being able to JOIN AND ATTEND.

Individuals who are WARY OF ARVS provide reasoning related to the difficulties with taking concurrent medication, the prevalence of side-effects, and the high pill burden.

Issues around COURSE OF DISEASE and STATUS ACCEPTANCE were similar to that established in focus groups A and B.

8. INTERVIEWS GROUP C AND D (NON-/INFREQUENT MEMBERS):  
RANKING CONCEPTS AND THEMES BY NUMBER OF ASSOCIATIONS (DENSITY)

It is now useful to rank all the original concepts (no = 48) with respect to their density (D); that is the number of links with other codes and themes as resulted from the links established in the diagrammes above:

CONCEPT	G	D	CONCEPT	G	D	CONCEPT	G	D
fractured family	14	10	employment	5	5	adherence	4	2
misconceptions	13	10	illness	4	5	family	3	2
distance (access)	26	9	communication problems	13	4	living away	2	2
not sick	7	9	making excuse	8	4	lifestyle choices	2	2
lack of money	7	9	marriage	7	4	course of disease	2	2
male	11	8	ARVS	6	4	pills burden	1	2
test	9	8	date of grant	5	3	HIV wellness	1	2
status acceptance	9	8	white car	4	3	alcohol	1	2
children	5	8	scary	4	3	waiting time	11	1
transport	20	7	husband	4	3	queue	10	1
time-consuming	6	7	pregnant	2	3	unsure of options	5	1
not ready	5	7	concurrent meds	2	3	MDRTB	4	1
stigma	10	6	HIV	10	2	hand-to-mouth	3	1
busy (LOGISTICS)	14	5	side-effects	5	2	knowledge	2	1
denial	8	5	OIs (opportunistic infections)	5	2	hope	1	1
caregiver	6	5	temporary living	4	2	contraceptive	1	1

**Table 15: Concepts ranked by density – Groups C and D**

## RESULTS FROM FOCUS GROUP E

### Group E participants: Chiefs of the Madwaleni, Mqhele, Bomvana, Soga and Melitafa Communities

#### 1. FOCUS GROUP E (CHIEFS): IDENTIFICATION OF CONCEPTS

The following concepts were identified from the focus group involving the chiefs, listed in alphabetical order (38 concepts):

Access	ARVs	autocratic leadership	canvassing community	children
Choice	community perceptions	confidentiality	course of disease	cure
Denial	disclosure	elderly	family	government
HIV wellness	illness	isolation	joining programme	lifestyle choices
making excuses	member follow-up	mutual support	Ols	partnering programme
Patientrights	reach of programme	recognising autonomy	respectforHCWs (health care workers)	scary
split SG	status acceptance	stigma	success of programme	support group mandatory
Test	transport	youth		

**Table 16: Concepts identified from Focus Group E (N=38)**

#### 2. FOCUS GROUP E (CHIEFS): RANKING CONCEPTS BY GROUNDEDNESS (PREVALENCE)

The simplest way of categorising the concepts is ranking on the base of the prevalence with which the issue (concept) is raised in the focus groups (G= well/poorly grounded). In addition, the frequency with which a particular concept is linked to another (in whichever except arbitrary way) is useful for analysis purposes (D= density). The latter is done later in the results section once the associations have been made between the different concepts and themes.

More analysis is understandably devoted to those concepts and themes containing well-grounded concepts and/or those concepts/themes that have a high density. Once all the quotations were analysed and categorized into the above concepts, the following groundedness (G) ranking was calculated:

CONCEPT	(G)	CONCEPT	(G)	CONCEPT	(G)
Stigma	12	scary	4	children	1
Recognising autonomy	12	split SG	4	choice	1

community perceptions	9	respect for HCWs	4	course of disease	1
joining programme	8	denial	3	transport	1
Disclosure	6	isolation	3	youth	1
patient rights	6	test	3	access	1
canvassing community	6	success of programme	3	making excuses	1
reach of programme	6	member follow-up	3	mutual support	1
Illness	5	elderly	2	status acceptance	1
partnering programme	5	confidentiality	2	support group mandatory	1
autocratic leadership	5	lifestyle choices	2	cure	1
HIV wellness	4	family	2	ARVs	1
OIs	4	government	2		

**Table 17: Concepts ranked by groundedness – Focus Group E**

### 3. FOCUS GROUP E (CHIEFS): MOTIVATION BEHIND GROUPING CONCEPTS INTO BROADER THEMES

There were fewer concepts identified in the transcripts of the focus group involving the chiefs as participants. This was because of:

- only one focus group
- fewer focus group participants
- being chiefs used to giving in-depth opinions on matters, the chiefs made longer contributions around fewer issues

As a consequence it became clear the number of themes would also be fewer than established from the other two focus groups. In light of this the choice of broader themes was more clear-cut than in the larger focus groups A and B.

### 4. FOCUS GROUP E (CHIEFS): CHOICE OF THEMES

Two sub-sets of concepts were neatly evident on analysis of the original list of 38 concepts.

1. UNDERSTANDING HIV AND THEIR COMMUNITY - Concepts were identified that were similar to those established in other focus groups around community members' reasons for joining or not joining the programme. The context in which the chiefs refer

to these issues is analysed, as well as comparing groundedness of concepts in different focus groups.

2. PARTNERING THE PROGRAMME - Concepts emerged around the theme of the chiefs' role in partnering with the programme management to achieve more success with the programme.

To allow for uniformity, some of the THEMES of other focus groups remain reflected in capital letters, despite not being regarded as a theme within this specific analysis of the chiefs' transcript.

#### 5. FOCUS GROUP E (CHIEFS):                    MOTIVATING FOR THE USE OF A THEME MAP

In the analysis of the transcripts, there were many associations established besides the grouping of concepts within the themes:

- Each concept within its theme is either positively (help), negatively (hinder), or neutrally associated with its own theme
- Some concepts are either negatively or positively associated with other themes and concepts
- Some concepts are notably not associated with other concepts and themes, against expectations concepts of different themes.

These associations are depicted pictorially below in THEME MAPS, in order to:

- Simplify and assist the discussion following in this research
- Allow for collating of the number of links associated with each concept and theme. This number is representative of the impact and influence of a particular concept, often independently of how many times the concept is raised in the focus groups. This influence of a concept is referred to its density (Grounded Theory).
- As an ongoing template to aid discussion amongst the HIV programme management staff when evaluating strategy and development of the programme

#### 6. FOCUS GROUP E (CHIEFS):                    INTRODUCING THE GENERIC OF A THEME MAP

The explanation of the use of the theme map (Fig 4.) is part of the results section for focus groups A and B; it is also applicable in analysing results of focus group E.

## 7. FOCUS GROUP E:

## ANALYSIS OF RESULTS BY INDIVIDUAL THEME

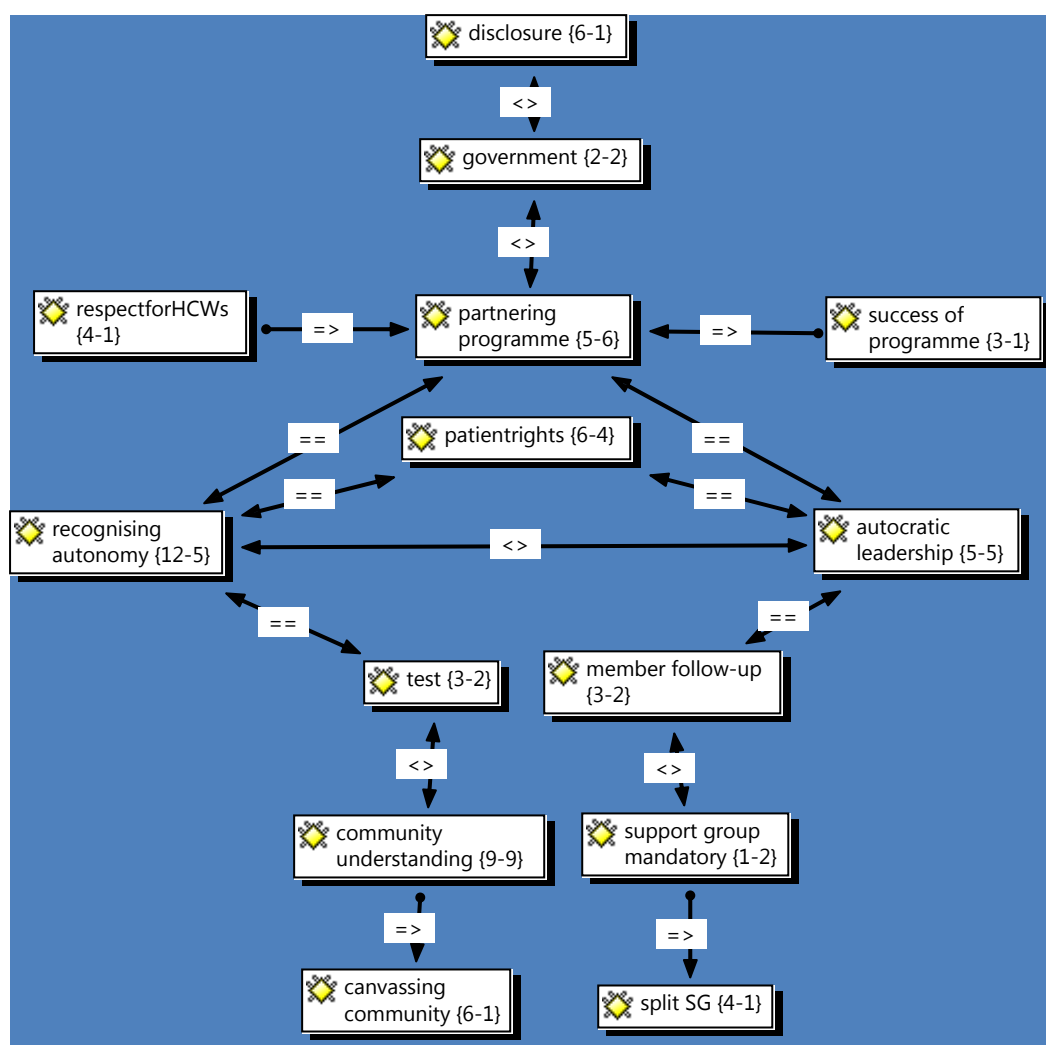


Figure 17: Focus Group E Theme Map: PARTNERING PROGRAMME

The concepts that are part of the general theme of PARTNERING WITH PROGRAMME are success of programme, respect for HCWs (health care workers), government, autocratic leadership, partnering the programme and recognising autonomy.

In witnessing the success of the programme, the chiefs are motivated to improve on PARTNERING THE PROGRAMME.

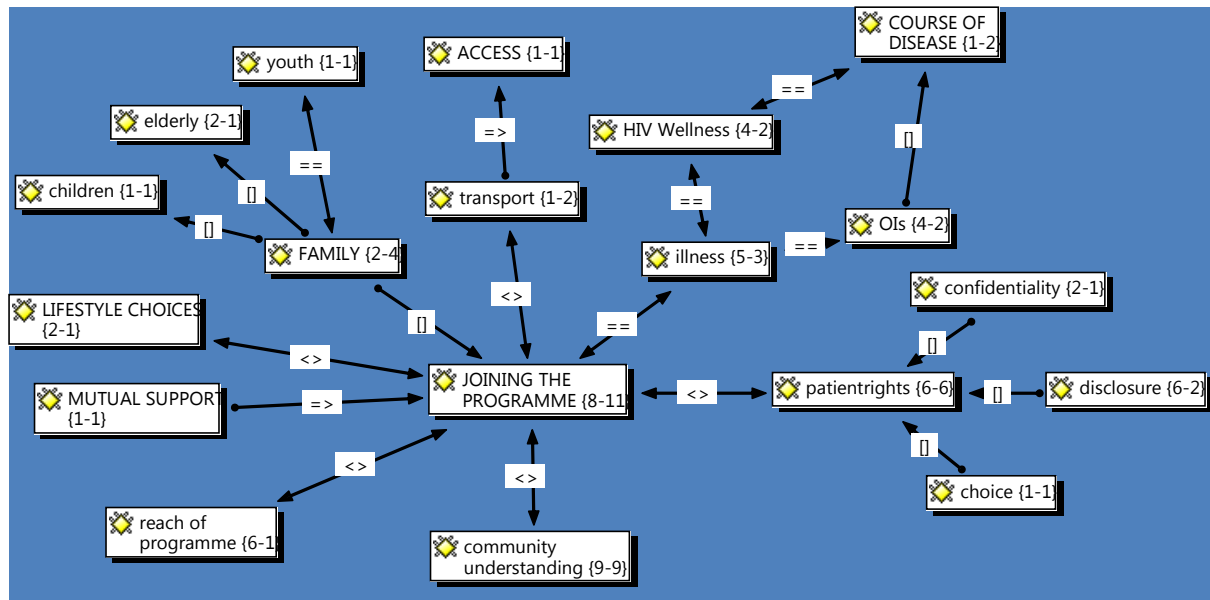
Contradictions are evident in the transcripts, notably between their respect for autonomy of the members/patients and the autocratic leadership style displayed. The transcripts acknowledge the practice of canvassing the community to gauge community perceptions around the issues of HIV in general. When members are defaulting attendance and ARVs, however, the emphasis around the role of the chiefs shifts from one of consulting to one of giving direction to community members in what is perceived to be their best interests.

In the interests of PARTNERING THE PROGRAMME to persuade people to join (or defaulters to follow-up), the transcripts revealed a propensity on the part of the chiefs to err on the side of an autocratic approach.

(cont...)

A respect for HCWs (health care workers) lessens the autocratic leadership style, and a compromise is reached: neither the authority of the community leaders nor the autonomy or self-determination of the individual is threatened.

Government is seen as being responsible for perpetuating some of the stigma and non-disclosure associated with HIV, by concentrating over-cautiously on confidentiality and recognising autonomy.



**Figure 18: Focus Group E Theme Map: UNDERSTANDING HIV AND THEIR COMMUNITY**

The concepts linked to the general theme of UNDERSTANDING HIV AND THEIR COMMUNITY are reach of programme, community perceptions, human rights, mutual support, lifestyle choices, family, transport and illness.

The chiefs understanding of the importance of the family unit is the same as the community, except the chiefs considers family as more of a help to JOIN AND ATTEND than is reflected in the other focus groups.

The chiefs' impression is that the reach of the programme, and the number of people on the programme, are both more than is actually the case.

Their understanding of the problems of the community perceptions is in keeping with that determined from the other focus groups.

On balance the patient rights relating to confidentiality and recognising autonomy are seen by the chiefs as conflicting with JOIN AND ATTEND

As outsiders to the programme, the chiefs see MUTUAL SUPPORT as more of a help to JOIN AND ATTEND than depicted in the transcripts of members A and B.

LIFESTYLE CHOICES is seen as more of a hindrance to JOIN AND ATTEND on a community level, as opposed to a neutral association in the other focus groups.

Transport is equally recognised as a hindrance to JOIN AND ATTEND by the chiefs as by community members.

(cont.)

Compared to illness, HIV Wellness has a more prominent place in the understanding and comments of the chiefs than that of the community, whether members or non-members (higher density of 6)

**8. FOCUS GROUP E (CHIEFS):**      RANKING CONCEPTS AND THEMES BY NUMBER OF ASSOCIATIONS (DENSITY)

CONCEPT	G	D	CONCEPT	G	D
JOINING PROGRAMME	8	<b>14</b>	support group mandatory	1	<b>2</b>
community perceptions	9	<b>10</b>	stigma	12	<b>1</b>
Partnering programme	5	<b>6</b>	disclosure	6	<b>1</b>
HIV Wellness	4	<b>6</b>	canvassing community	6	<b>1</b>
recognising autonomy	12	<b>5</b>	reach of programme	6	<b>1</b>
autocratic leadership	5	<b>5</b>	scary	4	<b>1</b>
patientrights	6	<b>4</b>	split SG	4	<b>1</b>
Illness	5	<b>3</b>	respect for HCWs (health care workers)	4	<b>1</b>
FAMILY	2	<b>3</b>	denial	3	<b>1</b>
OIs (opportunistic infections)	4	<b>2</b>	isolation	3	<b>1</b>
Test	3	<b>2</b>	success of programme	3	<b>1</b>
member follow-up	3	<b>2</b>	LIFESTYLE CHOICES	2	<b>1</b>
Elderly	2	<b>2</b>	government	2	<b>1</b>
confidentiality	2	<b>2</b>	ACCESS	1	<b>1</b>
Children	1	<b>2</b>	making excuses	1	<b>1</b>
Choice	1	<b>2</b>	MUTUAL SUPPORT	1	<b>1</b>
COURSE OF DISEASE	1	<b>2</b>	STATUS ACCEPTANCE	1	<b>1</b>
Transport	1	<b>2</b>	Cure	1	<b>0</b>
Youth	1	<b>2</b>	ARVs (antiretrovirals)	1	<b>0</b>

**Table 18: Concepts ranked by density – Focus group E**



## DISCUSSION

### DISCUSSION: FOCUS GROUPS A and B

**Group A participants: Staff and community members at Madwaleni**

**Group B participants: Community members at Xora Community Health Centre**

#### FOCUS GROUPS A AND B      THEME 1: ACCEPTANCE AND UNDERSTANDING OF HIV POSITIVE STATUS

The concepts within the theme of STATUS ACCEPTANCE fall in one of two sub-groups: those that hinder and those that help with acceptance of a positive status. Each concept in bold is part of STATUS ACCEPTANCE but falls in one of two sub-groups – those that hinder and those that help with acceptance of a positive status. Disclosure is recognised from the transcripts as the kingpin to the “helpers”, whereas community perceptions is the key hindrance that fuels other obstacles to an individual accepting his/her status, such as denial, excuses and the negative image of the white car that helps to ferry staff and members to and from clinics and homes.

Joining the programme by way of support group attendance is depicted as a hindrance to acceptance by an individual of his/her HIV positive status. An important role of joining the support group is to help an individual accept an HIV positive status; counselors even “tolerate” the denial of status by a member.

<p><i>someone, you'll find out that he didn't accept his status yet, but you find out that when he come here at Support group we are able to tolerate her/him, until she/he accepts his/her status...</i></p>
---

**Table 19: STATUS ACCEPTANCE quotation – Focus groups A and B**

It is clear that acceptance of his/her HIV positive status does not necessarily happen before (“b4” in table below) attendance at the support group; it is shown in the content of the transcripts to certainly not be a pre-requisite. It is, therefore, questionable whether programme marketing should push for individual acceptance of status before (b4) joining a group. In fact, the current focus on marketing the programme may be counter-productive – pushing a client to accept the reality of an HIV positive diagnosis without him/her actually experiencing the support and options available may cause further denial. A clear paradox is evident. Normality is the most highly grounded concept within the theme; individuals made it clear they do not want to be identified by their difference for having HIV.

	b4	b4	b4	b4
<b>NOW</b>	DIAGNOSIS	STATUSACCEPTANCE	JOINPROGRAMME	EDUCATION&SUPPORT IRREGULARATTENDANCE
Defines:	person	non-attendance	programme	

	b4	b4	b4	b4
<b>NEXT</b>	DIAGNOSIS JOINPROGRAMME STATUSACCEPTANCE EDUCATION&SUPPORT REGULARATTENDANCE			
Defines	person	programme	attendance	

	b4	b4	b4	b4
<b>IDEAL</b>	JOINPROGRAMME EDUCATION&SUPPORT DIAGNOSIS REGULARATTENDANCE STATUSACCEPTANCE			
Defines	group activity			

**Table 20: Process of STATUS ACCEPTANCE in an individual – Focus group A and B**

The initial fear of testing followed by the shock of being diagnosed HIV positive combine to elevate a diagnosis of HIV into the defining focus for the individual. Proper pre- and post-test counseling at the point of testing attempts to wrest some of this focus away on to a constructive plan going forward. These efforts notwithstanding, the system currently expects both diagnosis and status acceptance before joining the programme. A modification would be to properly allow for acceptance of status in the programme. Ideally, both testing and acceptance can happen within a programme, although the aim is to have all testing done as early as possible. Since testing might only happen later, the programme is then defined by another common task or objective, such as an income generation project – for which motivation to attend will be high by HIV negative and positive individuals alike.

One of the four basic elements of social bonding theory is attachment – the level of values and norms that the individual has in society (Hartwell 1999). There are many ways in which the sense of values and norms might be put to the test in the Madwaleni environment where poverty is rife, unemployment is high; families units are forced to break up in the interests of finding work only available further away; and chronic illness - whether HIV-related or not – is common. A solid foundation of attachment is therefore, difficult for an individual to attain.

Taking the above hardships as the worst, but all too common, scenario, the addition of an HIV positive diagnosis is difficult to handle on a personal level. With little to facilitate this sense of bonding, there is equivalently little to facilitate a newly-diagnosed HIV-positive individual accepting his/her status, especially where the diagnosis sets him/her apart from normality even further.

Once a member of the support group however, matters are very different. Each focus group participant is wholly accepting of his/her HIV status, a theme that is well grounded in the focus group discussions. On analysis of the relevant quotations, an unexpected finding is the role membership of the support group plays in assisting with this acceptance. Intuitively it is expected that acceptance happens as a prerequisite to the specific act of joining the programme, and indeed this is the case for some. For others however the acceptance process is a much longer one, starting at some point either side of his/her attendance at their first support group, but not wholly completed until some point in time later. Listed below are the quotes that relate to HIV status acceptance, as categorised by these criteria:

ACCEPTANCE OF STATUS BECAUSE OF JOINING SUPPORT GROUP	ACCEPTANCE OF STATUS BEFORE JOINING SUPPORT GROUP (OR NEUTRAL)
<i>I heard I had the virus and came here to the clinic. I had it, and I came and accepted (that I had) this virus.</i>	<i>When you live with HIV, and you accept it wholeheartedly, it is easy because you go with your treatment and take your medication.</i>
<i>I told myself that, OK, let me accept this thing that have been accepted by others.</i>	<i>I feel comfortable with this virus, because once you have it you tell yourself that you are going live like [many] other people.</i>
<i>it is very nice here with the Support Group because the people in charge, treat us nicely. Now then we have accepted this virus easily.</i>	<i>I don't have money when I am ill, but I am happy to live with the virus because I have accepted it.</i>
<i>No, me too I feel relaxed, it (support group) helped me to accept it, I thought that if I accept it, it would help me, and moreover, I became relaxed/comfortable..</i>	<i>It is easy to live with the virus and one should accept that you have it although it was not easy to accept it, but once you have accepted it, it is very easy and you feel 'light'...</i>
<i>They took me by surprise and I realized that I do not have to worry because I have accepted this and joined them and they will fix up this thing for me.</i>	<i>I feel very content to live with this virus, I don't see any problem. I feel comfortable.</i>
<i>Ja, like, the Support Group to me is very important because when I am here with the Support Group I find that those things that maybe I feel inside or maybe something I worry about in the way I see it, but then another person when s/he speaks about his condition, his illness, but I then see him as a person...</i>	<i>The only thing that prevents us from accepting it fully, is because we are very hungry. The things that we thought we'd get here from the Support Group, we do not see that we get them.</i>
<i>Yes, when I came here I found that there is a lot of people who are like me, I also accepted it then I noticed some healing in my life, yet I am healed.</i>	<i>Even the people of my home when I came and told them about my testing received/accepted me.</i>
<i>In my location people tend to point fingers at me I was crying every day, but after I attended the support group in 2005 I was brave and happy.</i>	<i>..now you have that thing so you end up even if you have accepted it, this problem of yours, you see it and accept that you have it but the people keep on pricking you....</i>
<i>now that we started we are better. I think we accepted and learned and we are able to educate others.</i>	<i>It was said I had the virus which I accepted and then I returned to join the Support group here.</i>
<i>support group helped me to accept that I have the virus, because this is the only reason I did not attend the Support group. This helped me a lot.</i>	<i>When I speak about this virus we are not scared of it, I can say 'I have this virus', I don't care about anyone, because there is the disease, doctors and nurses have it too. There is nobody immune to Aids.</i>

**Table 21: STATUS ACCEPTANCE quotations - comparison before vv. during JOIN AND ATTEND – Focus Group A and B**

The community perception of HIV is a general mix of individual approvals and prejudices. The transcripts suggest, however that the balance lies on the side of stigma and negativity surrounding HIV. The concept community perceptions is therefore depicted as a hindrance in STATUS ACCEPTANCE. This concept is not quoted, nor indirectly referenced, much in the transcripts (grounded no = 3) but its measure of influence on the other matters quoted above is significant (density =6). Unfortunately the “external condition” of systems theory quoted in the literature that helps to bind the support group members is the stigma around HIV (Schopler J., Galinski M., 1993). It is this stigma that currently defines the community perceptions, manifesting in concepts such as scary, such problematic HIV -associations as the white car (programme car used to ferry some

patients to clinic and back), and prompting of the expected denial when faced with the prospect of such stigma.

A solution may lie in exposing potential members – irrespective of the HIV diagnosis (known or unknown) - to a forum not defined by the HIV positive status of its members, but that provides education on the HIV-related services offered. For a non-tested member to be made aware of a potential HIV-positive diagnosis, outside of the (potentially threatening) context of HIV, is the perhaps the most effective tool. At a non-HIV focused, non-threatening, normal community event or gathering will be of help to expose and integrate the HIV support group members in the community as a group.

One may argue that the members themselves are their own champions within the community. There are, however, very few social and employment structures which may serve as the platform on which such “HIV wellness” may be observed and promoted. Church communities, schools, nursing colleges, even informal market gatherings at government pay point days may provide the backdrop for such interactions between HIV-positive members and HIV positive/HIV status unknown non-members outside of an HIV context, but these are few and underutilized in such a rural resource-poor community. Informal communal opportunities such as standing in a queue to pay a utility bill are rare where jobs and services are scarce.

The paternal dominance concept is the key concept within the FAMILY theme. Such dominance is also seen as a hindrance to status acceptance. The consensus amongst the participants (men included) was that an unproductive and frustrating pairing of social realities exists: men are often both the dominant party and the denialist, so the support of status within the family unit is often absent or even hostile.

<i>on the other side woman who are married do not come to support group, because sometimes the woman get tested positive and the husband did not test yet, so they don't come to support group.</i>
<i>but if the husband tested first the wife is comfortable to come to support group. But if is the husband did not test he does not come to support group.</i>

**Table 22: Paternal dominance in the FAMILY - Focus Group A and B quotations**

Understandably, there exists a pre-occupation with such basics as putting food on the table, staying warm at night and clothing the family in this impoverished community. This hand-to-mouth existence hinders an individual in accepting his/her positive status in a constructive frame of mind. While not universally felt by any means, amongst many there is a sense of resignation about HIV, childhood malnutrition, lack of jobs and services and other harsh realities of living in a poor marginalized community. This fuel any apathy felt towards self-acceptance and control of an HIV diagnosis. At the level of the programme, the attraction of certain material benefits (lunch provided at support group, select transport to-and-from clinic, the hope for a disability grant and the chance of a “stipend” for a member when working as a peer educator) may be the wrong reason for a person to get help in accepting his/her status, but such a motivation does help in JOINING THE PROGRAMME. The

positive effects of the MUTUAL SUPPORT once they have joined, places a positive spin on the initial “negative” reasons for joining.

<i>The only thing that prevents us from accepting it fully, is because we are very hungry. The things that we thought we'd get here from the Support Group, we do not see that we get them.</i>
---

<i>Others amongst us have no money and here we do not have money, we sit here and get hungry as we are squatting here, a person has to eat leftovers of yesterday which has been left at home early in the morning.</i>
---

**Table 23: Hand-to-mouth concept in REDEFINING DEPENDENCIES – Focus Group A and B quotations**

COURSE OF DISEASE is a theme detailed later in the discussion. On a community level, the required understanding of the importance living well with HIV, proactively taking steps to remain healthy and treat opportunistic infections does also not appear to be at a level where it can actively counter the paralysis and denial around status acceptance. Acceptance of status for most individuals relies on the more simplistic – but not superficial – help of mutual support by one for another.

#### FOCUS GROUPS A AND B: THEME 2: IMPROVING ACCESS TO CARE

<i>I wish that the support group does not meet. One can simply come and take, take the pills, and then go because we come from far places.</i>
--

**Table 24: ACCESS theme - focus groups A and B quotations**

The Patients Rights Charter lists access to quality health care as a right of all South Africans. In the Madwaleni context, provision of HIV programme services of excellent quality is of little comfort if the clientele are unable to benefit owing to lack of access. Analysis of these transcripts is a vital part of attempts to identify whether access is indeed a limiting factor for joining and ongoing attendance at the support groups.

Transport is provided by the programme (white car) on four select routes for select clinics to and from the hospital. Routes are chosen on the basis of numbers of members in the vicinity.

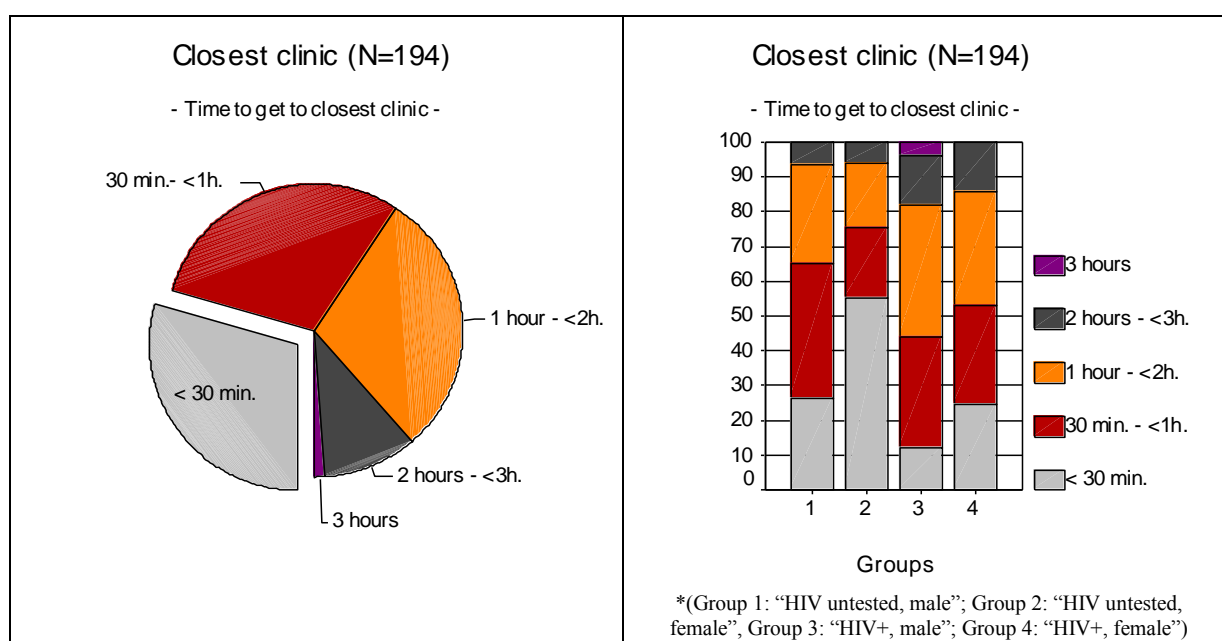
The problem with programme access is more complex than that explained by geographical distance, money for transport or the related issue of little money around for transport. Once members reach the facility (hospital, CHC or PHC), it is clear the difficulties with access and the impending return journey heighten sensitivities regarding queues and waiting times. Concepts within other themes are also a hindrance: illness also does little to help with “access” to the programme. Long queues resulting in excessive waiting times for an ill patient who expends precious energy in making the long journey to the health facility undermines other attempts to offer a good service at the point of delivery at the end of the queue. The concept “busy” was included under the ACCESS theme (unlike the other time-related problems) because it relates to the personal time of members, rather than time spent at the programme on clinic/support group day.

It appears the expected consequence of “living closer to a clinic than the hospital” does apply, namely easier access to primary health care. Participants at the focus group do by definition have access, so allowing them to join the programme. Access remains difficult for some, however, and discussion dominated a large part of the support groups. Remembering ACCESS is made up of three concepts related to distance: access, lack of money, and transport, plus a further four time-related concepts as being similarly hindering ACCESS: queue (for counselor or health professional), busy, waiting time and illness, all seven of these concepts hinder good access to care. Collectively they represent 91 quotations (although some duplicated between multiple concepts) of which 67 (74%) were from the Bomvana pilot focus group participants. Such primary health clinics are sometimes less easily accessed than the district hospital and the community health center (latter is based in a small town).

Madwaleni District Hospital	<i>most of the people stay very far, they do not hear what you are saying.....they will not be able to..... Some of them do not have that R5.00</i>
	<i>maybe someone come without money. They also get money for returning back home.</i>
Xora Community Health Center	<i>Another problem that we have is that people are staying too far from the clinic.</i>
	<i>Some people are willing to come and take their tablets but he/she does not have means of transport because she/he does not have money.</i>
Bomvana Primary Health Clinic	<i>...the only thing that is a problem is the exhaustion coming up this road. Haa! (No!)</i>
	<i>It's a long distance, if we walk, I walk for three hours.</i>

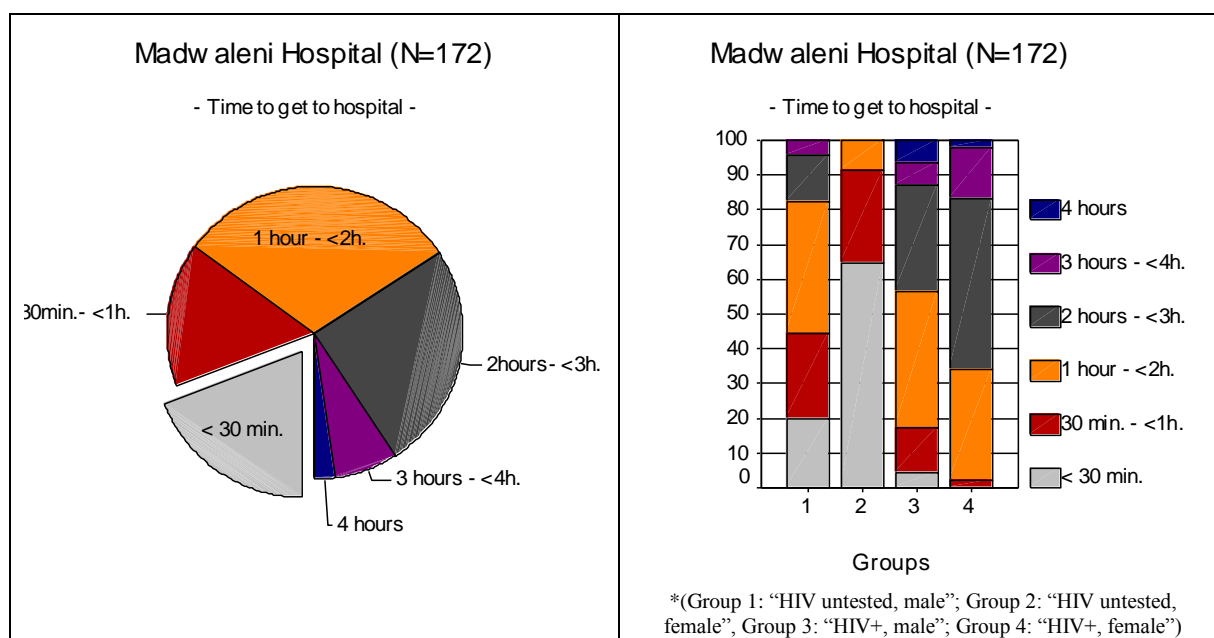
**Table 25: Problems with access at different health facilities – Focus Groups A and B quotations**

Decentralising health care to primary health clinics does not necessarily equate to improving access for some members. This is counter-intuitive, but for the accepted logic that “decentralized health care” equates to better access to care only relative to access to the hospital. It is incorrect to have the hospital as the reference point, rather than the patient.



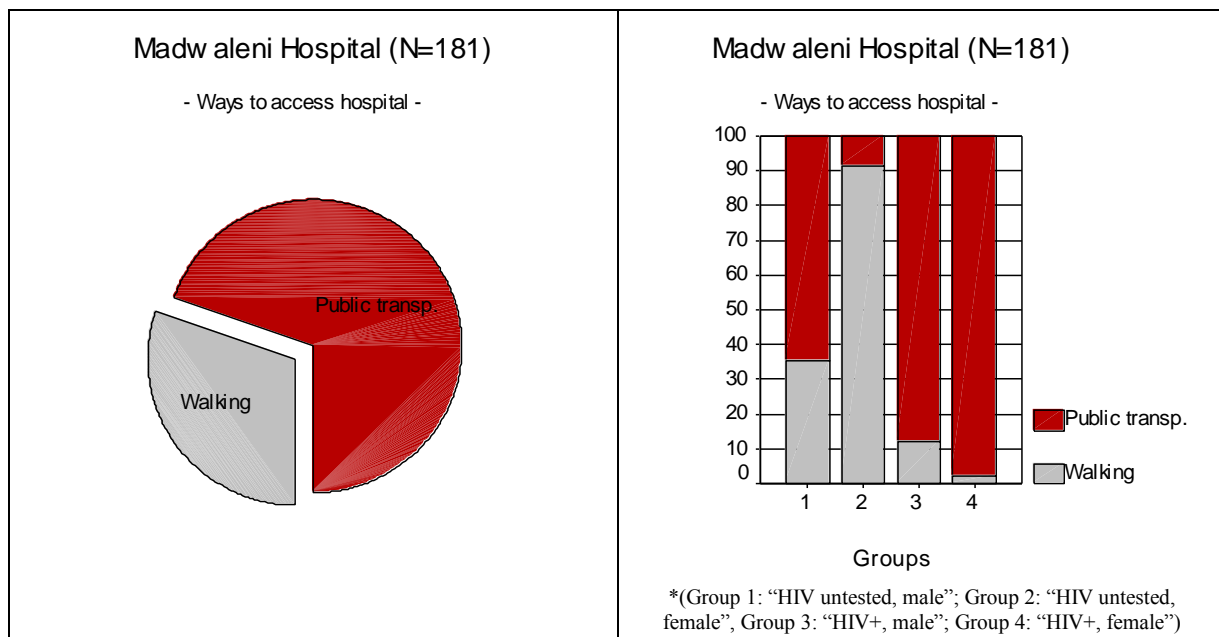
**Figure 19: Primary health clinics – Time to Access (N=172) (Winkel C., Cooke R., 2009)**

The two pie- charts above and below (Winkel C, Cooke R., 2009) show a similar length of journey (time) between home and clinic for some versus home and hospital for others. To provide a practical example, a man might have to walk for one hour to access his closest clinic that is poorly serviced by public transport, or he can walk for 25 minutes in the opposite direction, access a main road “line” more frequented by taxis, and be at the hospital in a total of 40 minutes.



**Figure 20: Madwaleni Hospital – Times to access (N=172) (Winkel C., Cooke R., 2009)**

It is clear a significant percentage of members are accessing the hospital by public transport. At best, this discussion can only speculate on the reasons for the opposite profile between HIV positive and HIV negative persons for their way of access, since the questionnaire-based study has not undergone a rigorous critique of the bias present in both sample collection and data analysis. The HIV positive members were sampled from the support groups, so they are programme members. That they predominantly use public transport may result from access to the programme transport that travels specific routes.



**Figure 21: Madwaleni area – Ways of access (N=181) (Winkel C., Cooke. R., 2009)**

Some differences between hospital and clinics do still apply. Everyone accepts the “unwell well” community members attend the clinic for assistance with minor ailments. The referral system allows, however, the more serious “unwell unwell” to be seen at the hospital. There is still the community perception that all health care revolves around the acute presentation. The perception is that the more ill the patient, the more likely he/she will need to be seen at the hospital. That leaves the chronically unwell patients who do not fit neatly into the management framework as understood by the primary health care nurse – and this group largely includes a fair proportion of the HIV positive members. They are unappreciated as a target sector of the population for intervention in the form of chronic disease workshops and support groups (of the sort offered by the HIV programme) at the clinics. The myriad of problems regarding preventative medicine is another debate, but the point is made that the HIV Wellness may be easier to promote at the peripheral clinics rather than the hospital.

Analysis of the transcripts raises the question of whether there is greater stigma surrounding joining the programme at the hospital rather than the community health centers and primary health clinics. The benefit the hospital gained in earlier years for taking on support group members from further away for reasons of stigma in their local communities was not unique to the hospital support group. Numbers at each support group have grown (now numbering 3760 in total, 08/2009); cross-pollinating has happened to the extent that the “benefit” no longer applies.

Given the lack of understanding of HIV Wellness, there may be a perception that membership is not necessary for the ease of access to the hospital. HIV positive people and others can lie safe in the (false) knowledge that if they fall sick, the proximity of the hospital will allow for help to be accessible and available. Not only does the community live near the hospital, but many know the staff members as neighbours and friends. With the stigma of joining, and the ease of access to care when one falls ill, why join before one has to?



These facts are sound, but the rationale is misleading. The best course of action remains regular medical checkups to identify and treat opportunistic infections early, and time the starting of antiretrovirals optimally through regular checking of the member's CD4 count.

Notably knowledge does not contribute to improving access to the programme. Defining knowledge as that gained within the support group only is deliberate. ACCESS as defined by continued attendance is enhanced. In contrast, community perceptions is hindered by a paucity of knowledge transfer and learning taking place outside the support groups, in the form of direct educational and communication events/gatherings for example. The concept community perceptions is therefore not enhanced by knowledge and remains a hindrance to STATUS ACCEPTANCE, as it is to ACCESS to care itself, although indirectly through the stigma around the HIV programme white car.

Waiting time is an example of a well grounded concept – on this basis it is placed in the “top ten” of all the concepts. This high ranking gains credence for the unambiguous, specific meaning of waiting time. To further illustrate this point: the only concepts referenced more in the transcripts that are not stand-alone concepts elevated for their broad meaning to THEMES, are material expectation, adherence and test. Unfortunately a well-grounded hindrance to programme success, excessive waiting time is a cause for concern. It is hoped that the recent opening of the Hobeni clinic and support group will reduce the numbers of people attending its two closest clinics, namely Bomvana and Madwaleni, so waiting times will be reduced.

#### FOCUS GROUPS A AND B: THEME 3: PROVIDING MUTUAL SUPPORT

The types of support available are clinical, material, social (group bonding, interaction etc.) and psycho-educational. Five distinct learning opportunities are available to members on any one support group day:

- Group education during the actual support group
- Individual counselling with the patient files (see file form in appendix 3)
- Education by pharmacy assistant when dispensing the ARVs (where those not on treatment are not involved)
- Nurse consultation
- Doctor consultation

Medical intervention, either preventative or treatment by the nurse or doctor, is an important part of the support that is provided. For its lack of reference in the focus groups, this clinical support is, however, not automatically included in the majority of member's understanding/definition of “support”. Within the support group context, the value attached to clinical support is not high, at least overtly – as a concept, clinical support was not well- grounded in the transcripts. It is rather support of a psycho-social nature (which comes in many forms) that is deemed the most valuable.

Of equal concern is the few times the individual counseling by the counselor or pharmacist assistant is recognised as an educational session, let alone approved of as a valued component to the HIV Wellness programme.

Value is attached, therefore, to social support above all else. There are numerous references to the support that the group provides. Importantly very little mention is made of the intervention of facilitators, whom in the Madwaleni case are peer educators and community health workers. This is disappointing given the value studies in the literature attributes to the role of facilitators (Schopler J., Galinski M., 1993; McLeod E., 1998).

It may be the focus group is not the best vehicle by which to gather the importance of the more intimate, confidential aspect typical to clinical support. Individual interviewing in a private, intimate setting is the preferable way for teasing out the merits of clinical and other forms of support that are unique to the individual. Generic topics such as side-effects of ARVs can be taught, understood and discussed generically in a support group, but clinical support is largely provided outside of this forum; its importance is understandably underestimated.

As outlined in the literature review, were the Madwaleni facilitators to take a more proactive role, the evidence favours an equitable balance between them providing interventional support with psycho-educational tools, while allowing the group the breathing space to develop the supportive synergies for themselves.

Removing the theories of psychological support into a more practical context, it is the very HIV positive status of the counselors and peer educators that places the differences between the theories in context. Very rarely do such theories recognise the similarities between the therapist and the "patient". At best, comparisons recognising that existentialist therapists take a more nonjudgmental attitude towards patient' previous decision-making and openly function as role models by sharing more of themselves than Freudian therapists do (Shaffer J. & Galinsky M. 1989). There are, however, 5.5 million HIV positive people in South Africa alone, the disease affects every stratum of society irrespective of education levels; it is completely integrated – often the therapists are patients on another day.

A key question is whether to capacitate these counselors themselves or rely on health professionals: psychologists, social workers and others. It is clear the line must be drawn; the skills and experience to deliver assistance increase in proportion to the complexity of problems presenting, but where to draw this line exactly? Skill is also neither a synonym for experience, nor vice versa. Task shifting takes on a special importance in the setting of HIV, a pandemic whose numbers are huge, including at Madwaleni. Furthermore, with a doctor-patient ratio of 3 for every 100 000 in rural South Africa areas including Madwaleni, shifting tasks to the lower staff levels is vital to get the job done.

Historically the HIV programme coordinator has not been able to devote full training resources to “train the trainer courses”. Courses on bereavement counseling, couples counseling, and adherence counseling, have been provided, but the baseline peer educators’ baseline low level of education, plus the absence of any formal health training, results in much time being devoted to factual learning rather than improving both support group facilitation and individual counseling.

SUPPORT FOR HIV+ STAFF AND PATIENTS	STAFF SUPPORTING PATIENTS (COMMUNITY MEMBERS AND HOSPITAL STAFF)	PROGRAMME MANAGEMENT SUPPORT FOR STAFF
<i>When I looked at this room where I am now it was full of people, they have this same thing I have, so now then what is it that will make me unable to live? (Patient)</i>	<i>And they do have support from at- some people like there like there is a Support group here at Clinic so they do have support and they have drugs here at Clinic</i>	Not referenced
<i>(the) support group helped me to accept that I have the virus, because this is the only reason I did not attend the Support group. This helped me a lot. (Staff)</i>	<i>I has already said we are following them in order to come to support group. Even if a patient is tested positive just disappear, we don't just let it go we try to follow him/her.</i>	
<i>I had no one to see, but the day when I started to come to the Support Group, I heard the opinions of others about Aids, and I mean if you are positive it does not mean that your life is over, you can live a long life. (Patient)</i>	<i>So support group is helping because they get support from each other.</i>	
<i>In my location people tend to point fingers at me I was crying every day, but after I attended the support group in 2005 I was brave and happy. (Staff)</i>	<i>But I just want to say that eh-e-, if, its different for a parent who is HIV positive because if the parent has got a child and is coming on Wednesday, that parent doesn't got a-a-, doesn't get support group for herself or himself.</i>	
<i>But the day when the Support Group arrived with the testing we started to get well and then I saw that the Support Group is important because many people got well. If a person now still wants to die, that is his choice.(Patient)</i>	<i>It's fine for, for that one but for the one who is HIV positive with, with the child it's not because the parent is not getting support its only the child who get who is getting it, who's is getting something.</i>	
<i>the worst part was that I knew that when you are HIV positive I am going to die. So in the support group I learned that it's not like that. (Staff)</i>		

**Table 26: MUTUAL SUPPORT for staff and programme members – Focus Groups A and B quotations**

Looking at the individual quotations themselves, there is nothing to distinguish the comments as made by staff or patients. Exactly the same range of vulnerabilities, concerns, beliefs and other emotions are experienced by everyone. A staff member may admittedly gain personal support having to provide support for others, but this is an assumption. Admittedly, timing may be the key distinguishing factor – staff may feel more comfortable with the personal support gained over time, and quotations above are related to different times along personal journeys with HIV. There is no

reference to the support that the programme management provides for the staff, if at all perceived to exist.

A logical source of mutual support within the support groups should be religious faith. The Xhosa people are largely a community of committed Christians, devotedly reliant on their church and faith for guidance, solace and support. It is therefore of interest that reference to religious faith was made once in the transcripts. The programme management would be wise not to disregard such respected faith for it not being referenced, but rather look to understand how the programme has been inadvertently developed and structured to quell this normally fervent source of personal support.

#### FOCUS GROUPS A AND B      THEME 4: REDEFINING DEPENDENCIES

Dependency can be viewed in two distinct ways. The meaning is - as defined when recognising themes in the focus group transcripts - to describe a “negative” form of support designed as a crutch, not as a form of dependency designed to facilitate the individual’s efforts in self-development. Members by that definition develop a dependency on money for transport, food parcels, and grants of various forms (disability, child care, care dependency, foster care grants). That these grants counteract reliance on self-development is not always the case, and judgement can not be passed on community members reliant on such grants when no alternative is available. Abuse and mismanagement occur, however, by recipients and government custodians of the grant system respectively.

As a health programme, the alternative definition of dependency the programme wants to promote and foster is one related to psychosocial support of each other as programme members. With the aim of HIV positive individuals joining and regularly attending the programme, value must be attached to the support provided. The benefits of a “positive dependency”, in the form of bonding, sharing experiences and educating each other, are well appreciated and valued. The extent to which this value exists, however, centers mostly on living with the HIV virus: initial acceptance of HIV positive status and understanding the importance and challenges of taking life-long medication. These are vital educational goals; any HIV programme in its infancy must be “viral-centric”. As the programme evolves however, and the systems/ expectations are such that the acceptance of living with HIV becomes more automatic, then the shift has to change to HIV Wellness and then on to normal healthy and productive living. Facilitating this change is crucial; left to themselves there is a danger members will foster self-promotion and development through the use of their HIV status alone, setting themselves apart for their difference, not their potential.

The wish to be employed is not mentioned as much as one would expect in a community with 86% unemployment. One can speculate whether the prospect of work is simply not contemplated as the opportunities themselves are so scarce – or a sense of entitlement prevails – fuelled by their awareness of the vulnerability conferred by an HIV positive status. From the transcripts, it is clear each person’s perception of his/her need is independent of the formal needs-based selection criteria

established by the Department of Health or Social Development. Attendance at the support group can in fact foster “negative dependency” on applications for disability grants in the absence of a disability - unless specific counter-measures are proactively taken by group facilitators to guard against the powerful draw of a government grant.

While tempting for the health professional to over-apply for grants in the face of few other options, doing so only serves to facilitate this dependency.

In the theory of behaviourism, the importance of the mind is controversially dismissed – thinking and emotions were regarded as irrelevant (Watson J. 1913). With regards to this HIV programme, the importance of patient autonomy, as well as promotion of an equal health professional – patient relationship have been well-advocated during this discussion. In fact, the premise on which the focus groups were conducted was the lack of canvassing community views at the time of structuring the programme. It is therefore with ease that this aspect of traditional theory of behaviourism (Watsonian theory) is argued as unsuitable in the Madwaleni context.

Behaviourism does also, however, suggest observed stimuli and responses can be used to explain behaviours (Watson J. 1913). There is no denying that the difficult environment in which Madwaleni community members attempt to survive provides numerous stimuli to evoke responses – responses that manifest as dependencies as described above. Applying a type of behaviour therapy called token economics, the use of a reward system to reinforce preferred behaviours may be useful. Training projects, food garden, looking after young children, tracking patient defaulters are all examples of projects that need the initial impetus before the benefits of involvement are well-understood and appreciated by the participants for their early experience. Just as in typical behaviour therapy, token economics must not create a dependency economics in itself, but can yield results if well-managed. The current Madwaleni practice of paying stipends and monetary incentives to staff members to do additional tasks is not too dissimilar. The practice could be extended to members and non-members, budget allowing.

#### FOCUS GROUPS A AND B:    THEME 5: AWARENESS OF THE COURSE OF DISEASE

Members’ motivation for mutual support is related either to the search for meaning or as a means of adapting to external conditions, as suggested in the literature on existentialism and systems theory respectively (Schopter J., Galinski M., 1993; Yalom D. 1998). The transcripts show that meaning in this HIV support group setting centers on bonding over the personal struggles around acceptance of HIV positive status rather than issues of HIV wellness and slowing the course of the disease. Again by systems theory, the “external condition” of stigma around HIV dominates the group dynamic more than the “internal condition” of trying to collectively promote each person’s HIV Wellness. Were the purpose of the support group to shift to managing internal conditions of HIV Wellness and the course of the disease (both relatively poorly grounded compared to STATUS ACCEPTANCE), then systems theory suggests the bonding forces would fail without another external condition to replace.

<p><i>The Support Group and Wellness I know is about who do not eat herbs but take bactrim and folic, bactrim and folic acid and bico or another person perhaps you find that he takes folic and bico. So it depends on your CD4 cell count, so if it is above 350 we give him folic acid and bico and if it is below we give him bactrim and folic acid and bico. So, that is Wellness.</i></p>
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**Table 27: HIV Wellness in COURSE OF DISEASE theme – Focus Groups A and B quotation**

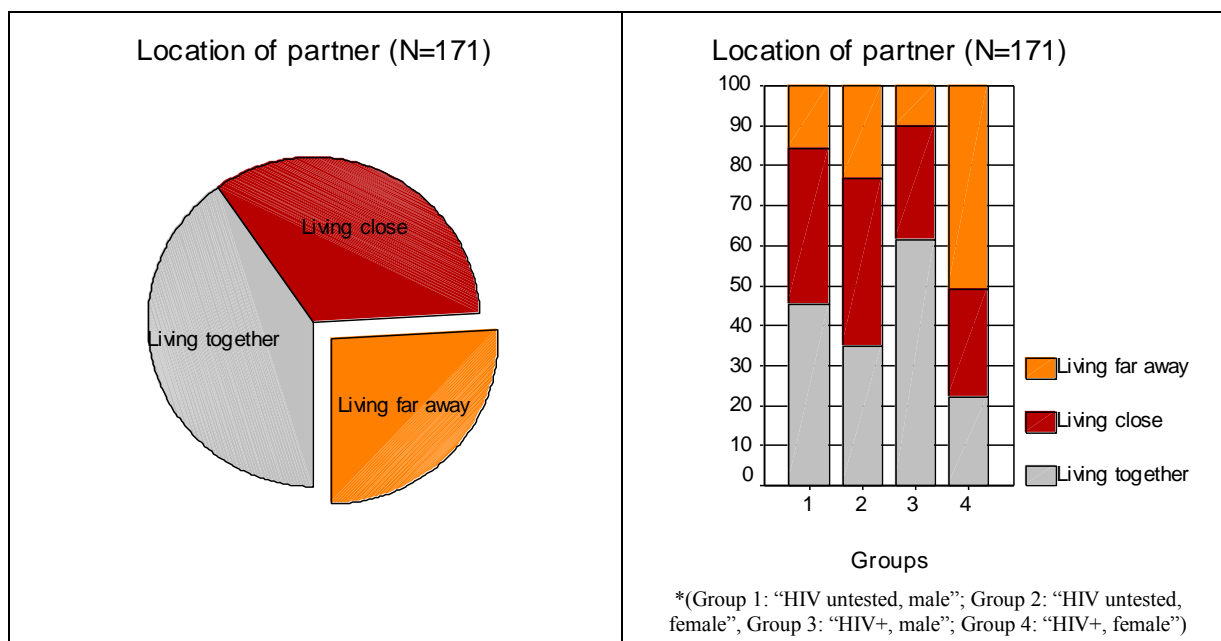
To underline the seriousness of the degree to which the course of disease does not feature as a important factor, it can be remembered that, while disclosure (of status) is listed as the key “help” to acceptance of a positive status (see THEME 1), it is this very association that undermines any strong influence such disclosure may have on influencing a member’s perception of controlling the course of disease.

Figure 9 (depicting the theme of COURSE OF DISEASE) is noteworthy more for the associations that are not present, than for those that are. Each of the concepts healthy, illness, test, and HIV wellness is part of the theme COURSE OF DISEASE. It was clear from the transcripts however, that there is no direct link between the MUTUAL SUPPORT and COURSE OF DISEASE. The link is indirect and narrow; it arises specifically through the latter theme’s concept test and the general theme of STATUS ACCEPTANCE.

#### FOCUS GROUPS A AND B: THEME 6: IMPORTANCE OF THE FAMILY UNIT

The central message illustrated by the associations between FAMILY concepts is the far-reaching effects of the paternal dominance in family unit that is so prevalent in Xhosa society. Understandably, paternal dominance has a negative effect on the mutual support provided in the support group. The opinions expressed do not suggest the men present at the support groups discourage equitable interaction between them and the women present. It is rather thanks to a combination of their relatively few numbers on the programme and the subordinate role the women have in the home environment that does not allow for mutual support as a general, although certainly not absolute, rule. Broken family structures (men away in search of work) also contribute to this lack of family support. The men’s lack of involvement underlines the fact that community perceptions of HIV is at odds with an individual’s acceptance of his/her HIV positive status.

Demographic data concerning the family unit is shown as follows; the numbers of partners living far away, predominantly the husband, is significant:



**Figure 22: Location of partners of the Madwaleni community (N=171) (Winkel C., Cooke R. 2009)**

In theory, the reason for locally-based men not attending the support groups is neatly explained by the group not being structured as a problem-solving forum – a necessary step to invite the initial interest and sustained involvement of men, as detailed in Coping Theory (Lazarus RF., Folkman S. 1984) The literature (systems theory) also recognises that task-oriented group leadership is as beneficial as social-emotional leadership; the former is preferred by men (Adamsen, L. et al. 2001).

There are 638 men (33%) compared to 1309 women (67%) on antiretrovirals as at July 2009 (Madwaleni database, 2009). A quick assessment of the main support group attendance register over the four weeks in May (random month) indicates that the split between men and women attending the Madwaleni support group reads as follows:

Gender	supportgroup05/05	supportgroup12/05	supportgroup19/05	supportgroup26/05
Male	24 (32%)	20 (30%)	17 (28%)	18 (32%)
Female	50	47	43	38

**Table 28: Support group attendance – men versus women Madwaleni mid 2009**

That steps need to be taken to attract more men as long-term members is not up for debate; the comments in the transcripts lament the absence of men and the programme “numbers” as shown in the introduction back these assertions as far fewer men join the programme.

There are conflicting views around the place of children in the hearts and minds of the community members. Anecdotally, the observation is that when a patient is asked who he/she lives with, the number of children is not included in the immediate answer. The question “And children?” must always be added. Conversely, children was a fairly well-grounded concept in the transcripts (16); there are expectations that the programme does need to cater for children and their needs. A further

categorization of children is those that are deemed orphaned and/or vulnerable (OVC); since Dec 2007 the OVC programme has been operational at Madwaleni and four of the seven clinics. To date there are 1203 such children registered on the programme (Madwaleni database, 2009)

While pregnant women were excluded from the sample chosen for the focus groups (hence the concept prevention-of-mother to child transmission PMTCT is poorly grounded), there is logic to the targeting of young women for prevention and programme membership (if HIV positive). In the management of both HIV and obstetrics, it is far easier to have these women fall pregnant while on the programme than off, for reasons that family planning may be more easily implemented (complex with couple counseling) in the first place, time may be taken to teach about HIV and vertical transmission, higher risk pregnancies can be detected earlier and the chances are better for having the pregnant woman on antiretrovirals at the optimum time in her pregnancy. Pregnancy was not discussed by the focus group participants, but targeting young women of reproductive age, as well as strengthening the systems around PMTCT may anecdotally have good benefits.

#### FOCUS GROUPS A AND B: THEME 7: IMPACT OF ARVs (ANTIRETROVIRALS)

The concept ARVs is one of the most grounded of all the concepts identified in the transcripts (53,3). It can be reasonably deduced that the single most important reason the majority of people attend the support group is to be given the ARVs. While members place much emphasis on the benefit of the bonding and sharing experiences (see discussion on MUTUAL SUPPORT theme), there is much to suggest that the great majority would not attend were they not receiving antiretrovirals. Indeed there are some quotations confirming the tendency of some to come for collection of the medications after which they leave, particularly the older men.

Of interest is that the concept ARVs is not associated with a high density in the transcripts. Of the few concepts that form part of the theme, it is in fact adherence that is networked with so many other facets of the programme. For a well-grounded topic (of over 50) that is popular and well-understood, ARVs is often quoted in isolation.

Of particular note, is the lack of association with HIV Wellness. Not a single quote was categorised for the ARVs and HIV Wellness concepts together. This suggests a poor perception of the value of both starting and continuing the medication as a health prevention/illness prevention tool, rather than for the more simplistic of treating the effects of the virus.

It is clearly evident however that adherence to the ARVs is foremost in the minds of most of those members on the life-long medication. Of the 53 quotations attached to the ARVs concept, a full 20 include a reference, direct or implied, to the importance of adherence. To illustrate this, a sample of such quotations is listed below:

---

*When you live with HIV and you accept it wholeheartedly, it is easy because you go with your treatment and take your*

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---

*medication that you were given and you listen to what you are told.*

---

*it is something I like because we are given various things to help, the pills, we take pills , and if you take them nicely you yourself feel Hey! I am that person that I was, and you do not feel as if you are another person.*

---

*Now if I had not been part of the Support Group, we would not have known. Because of the advice we get, you are well, you take your tablets that are given to you.*

---

*It's been a long time I used these tablets and I do not default because I am still continuing my treatment*

---

**Table 29: Adherence concept in ARVS theme – Focus groups A and B quotations**

Adherence, as measured by the number and consistency of repeat visits to collect medication, is high. A less direct but relevant measure of adherence is the overall level of viral suppression in members on ARVs. To re-iterate this outcome measure as detailed in the introduction: for the 1343 members started on ARVS at Madwaleni between July 2005 – Dec 2008, virological suppression (<400 copies/mL) were 87%, 87% and 88% respectively for years 1, 2 and 3 (Leisegang R. et al, 2009). It is no surprise, therefore, that the concept adherence, dominates in the discussions amongst the focus group participants for its importance in their daily routine.

Of interest is the way some members subvert the long waiting times by having a co-member register them before they arrive. They are then in line for earlier dispensing of antiretrovirals, the queue for which is based on the initial order of registration on arrival.

Of concern is the myth that the antiretroviral treatment collectively needs to be taken with food. This association arose in each of the focus groups, and two examples are given below:

---

*As we stay here at the homes, you will find nothing to eat but one is forced to take these ARV's, the ARV's make one hungry. So I am asking if there isn't a way that we can receive monthly food parcels*

---

*It is 12,5 (kg maize meal) , if you are given one and eat from it dry, even if it has no fat now then when you take these pills. You get dizzy and fall down. I once fell over when I thought I will borrow money because I don't have money. I was fetched from the fields.*

---

**Table 30: Hungry concept in ARVS theme - taking ARVS with food – Focus groups A and B quotations**

Xhosa communities are not unique in promoting the importance of taking food with any medications; a similar understanding in many communities worldwide. This broad assertion is, however, not entirely backed by sound scientific fact. The perception has now extended to include taking of antiretrovirals - even broadening the association to the idea that the medications induce hunger – when in reality such antiretrovirals as efavirenz are best taken on an empty stomach. While gastro-intestinal side-effects are experienced with ARVs, food intake is more associated with the efficacy of the treatment rather than precipitating of side-effects.

## FOCUS GROUPS A AND B: THEME 8: KNOWING THE VIRUS

There were only two factual inaccuracies quoted by the focus group participants. Both of them, however, involved the component concepts within the VIRUS theme. The first quote concerned the transmission of the HIV virus:

*PA: But now they know that HIV is like other diseases. They know that HIV is not transmitted through sexual intercourse only, it transmitted through many things.*

**Table 31: Transmission concept in VIRUS theme – Focus groups A and B quotations**

There was a perception that HIV is transmitted through “many ways” – strictly speaking this is correct as vertical transmission does make up a significant proportion of HIV transmission. This speaker however, did not have vertical transmission in mind when making this comment. While tempting to allow a misconception to lessen the stigma around HIV as a sexually transmitted disease, the message of the dangers of unprotected sex as the route to infection must be unequivocal.

The second area of inconsistency involved the inaccurate distinction between HIV and AIDS. In six of the seven quotations including the concept AIDS, AIDS was referred to inaccurately or the clinical syndrome was used in the incorrect context.

INCORRECT	<i>It is easy to live with the virus and one should accept that you have it although it was not easy to accept it, but once you have accepted it, it is very easy and you feel 'light' to such an extent that my body feels 'light' since I have accepted Aids.</i>
INCORRECT	<i>I had no one to see, but the day when I started to come to the Support Group, I heard the opinions of others about Aids, and I mean if you are positive it does not mean that your life is over, you can live a long life.</i>
INCORRECT	<i>about the home visit I like it very much, on the other hand the people in the community when maybe it is only you with Aids you feel you have a problem of being ill and the people tend to make funny comments about the car and they say Yhu!</i>
INCORRECT	<i>We see it as late for the children, this thing that the children when you are pregnant they be checked , it is late, because now then he may have Aids too the child because when you fell pregnant you had Aids and he may also then get it.</i>
INCORRECT	<i>I also say that the testing of the children for Aids is right because I too was pregnant. During my testing for Aids when I was pregnant I was worried that maybe he will be born having this Aids because I had this Aids.</i>
INCORRECT	<i>Government should make a plan so that Aids can be cured. Let it come with medicine that can get rid of this disease, so it can stop totally. We accept it simply because we are forced to.</i>
CORRECT	<i>It means you are not in the stage Aids, but you are HIV positive, you can work, study and you will live a long life and fulfill your needs.</i>

**Table 32: Inaccuracies in understanding concepts of HIV and AIDS – Focus groups A and quotations**

The virus concept has a density of four, the links with other concepts being AIDS, HIV, test and knowledge. Understandably there is a common quest for knowledge that binds the members in MUTUAL SUPPORT, and the other three concepts are logical partners in the VIRUS theme. The

common mix-up in understanding of the correct differences between HIV and AIDS has the latter being depicted as a "hindrance" concept within the VIRUS theme.

#### FOCUS GROUP A AND B:      THEME 9: THE RIGHT LIFESTYLE CHOICES

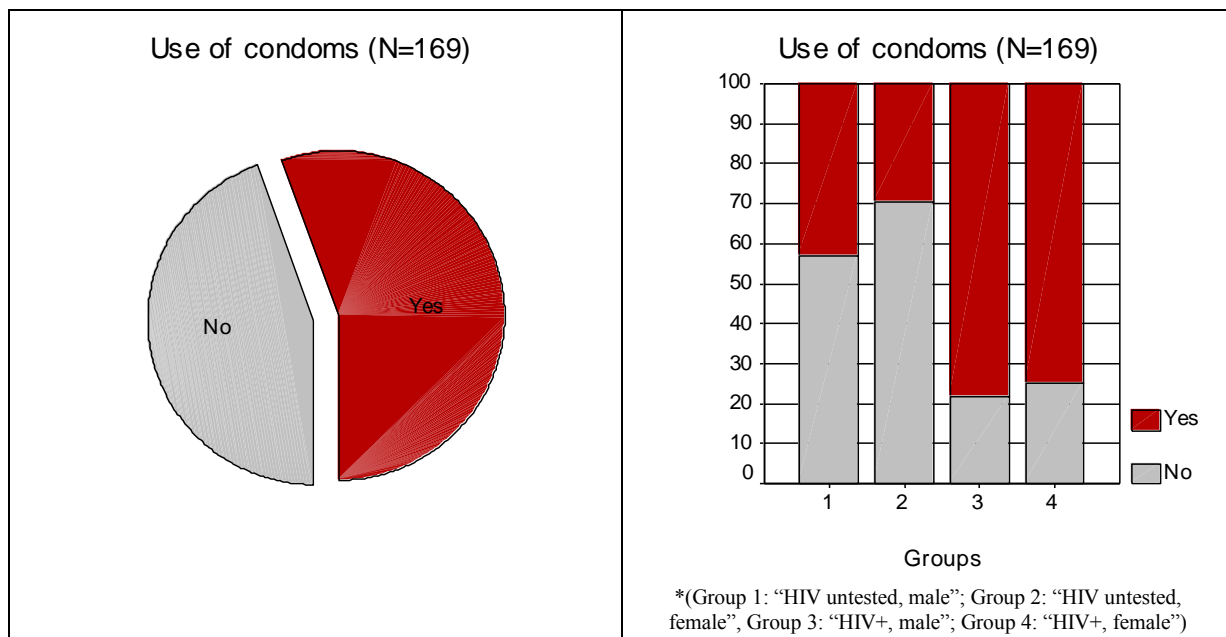
The LIFESTYLE CHOICES concepts are not well-grounded as a group, condomising (safe sex) is not well-discussed in the focus groups, and alcohol/smoking mentioned a few more times). Their influence on programme members is, however, made clear when remembering it is not only negative character traits that can be classified as lifestyle choices. The success of antiretrovirals is dependent on habitual adherence, and the supportive environment is the key to facilitating an individual making the right choice to be adherent and remain so, forgoing the negative influence of other unproductive and destructive choices. The concept of adherence is very well grounded (20,10) and it is within this strong culture of adherence that the other habits are judged to be wrong. The concept adherence is categorised within the ARVS theme for the obsession with antiretrovirals but could as easily find a place in the LIFESTYLE CHOICES box of concepts.

Once again the HIV Wellness concept stands alone. The importance of adherence is simplistically linked to ARVS alone in the mind of the member, rather than the subtly different but important goal of perpetuating HIV Wellness.

Research and evidence aside, logic and experience suggest having bad habits of alcohol, smoking, and unprotected sex is relate as much, if not more, to external circumstance as to inherent character weaknesses. Lifestyle choices are heavily influenced by the environmental factors – family is a fairly weak motivator to choose the preferable habits and lifestyles, as an often-fractured entity between migrant labour and the devastating effects of HIV. This reality, alongside the disruptive effects of paternal dominance, reduces the efficacy the family unit as a support tool for appropriate lifestyle choices.

Everyone has vices and those with HIV are no exception, but there is certainly no evidence in the transcripts to suggest being HIV positive pre-disposes to greater participation in “bad habits” than those who are HIV negative. There is clearly, however, not the maturity to promote the practice of “some things in moderation” with respect to alcohol intake.

Treatment partners were not mentioned in the focus groups, despite the programmes insistence on their involvement before a person starts ARVs (Appendix 1). Where the treatment partner is a family member (often the case), it seems the negative effects of a fractured family, as well as the poor community perceptions may negate the positive effects of the support given by the treatment partner on an individual level.



**Figure 23: Condom use by sexually active Madwaleni community (N=169) (Winkel C., Cooke R. 2009)**

The questionnaire study showed a high proportion of the community who do not practice safe sex, but more members wear condoms than those who do not know their status. There is some reason to believe that the topic did not come up in the focus groups as the facilitators inadvertently guided the discussion in another direction, but it is clear that the topic remains, to a certain degree, taboo.

Religious faith is again noted to be a poorly-grounded concept. It fits rather awkwardly in LIFESTYLE CHOICES, where it may be better suited to the theme of MUTUAL SUPPORT. Remembering this theme is mostly the support as provided by the support group vehicle, however, religious faith was not raised as relevant in this context. This finding is contrary to expectations, since the community itself is deeply steeped in religious faith and tradition. That the programme was not founded with religious/missionary goals as objectives, may be responsible for dampening the positive impact that religious faith could have had in meeting the needs of the programme members.

#### FOCUS GROUPS A AND B: THEME 10: ENCOURAGING JOINING AND ATTENDANCE / BEST SYSTEMS & STRUCTURE

Of the ten themes, the one JOIN AND ATTEND is given the alternative name of SYSTEMS AND STRUCTURE. The latter tackles those "demand factors" as set out by members and non-members alike, which should influence the supply of programme systems and structures to meet their needs as HIV positive individuals. Since analysis of this theme most closely answers the research question of why people do or do not join the programme, discussion of this theme attempts to summarise the findings after the discussions of findings from the other focus groups: Groups C and D (non-attendees and non-members) and Group E (Community leaders).

## DISCUSSION: GROUPS C and D

**Group C: HIV positive individuals who have not joined the programme (individual interviews)**

**Group D: members who attend infrequently (focus group)**

There were many reasons for why HIV positive members were not joining the programme that were identified in the focus groups consisting of staff and current regular members. Many of the same issues were raised in the individual interviews/focus group conducted with non-members and infrequent attendees respectively. That the concept community perceptions is a hindrance rather than a supportive help has emerged in the analysis above, and this was borne out by the comments made within Groups C and D. Stigma remains an issue, the white car carries more negative imagery of HIV than first thought by programme management, and disclosure is not the norm – especially by the men.

For many however, it appears problems with joining are largely logistical. Access is a real problem for some, despite decentralizing the provision of care to the clinics. A proportion of those tested are part of the transient community of the region – they are temporarily living in Mbashe because they are looking for work in East London or traveling between family members elsewhere in the country

<i>I came the first time, then my husband told me to come to Rustenburg , he's working on mines. I stayed there four months</i>
<i>My daughter has a file at VCT (clinic). I am happy she is taking the medicines. Me, I have to look for work in East London, I have been to a clinic near Frere (hospital in EL)</i>

**Table 33: Concept of fractured families in FAMILY theme – Groups C and D quotations**

The last of these comments was made by an HIV positive woman who was not on antiretrovirals, but had a CD4 count of 144 – well below the minimum threshold for starting antiretrovirals.

Anywhere along the “educational road” – be it at the point of VCT counseling, individual counseling, support group educating or adherence counseling, there are a number of varied and fairly complex subjects on which to educate HIV positive individuals. Some subtle misinterpretations may have far-reaching consequences on the understanding and subsequent behavior and action by the individual receiving the educational message. There are a small proportion of members and non-members for whom the transcripts of interviews demonstrated that despite the efforts to educate and counsel patients, a clear message was not getting across.

EXAMPLE	FACT	MESSAGE GIVEN	MESSAGE RECEIVED (QUOTE)
TREATMENT	Efavirenz is teratogenic in pregnancy	You cannot fall pregnant on efavirenz (message) You must not fall pregnant on efavirenz (message)	<ul style="list-style-type: none"><li>• Five rands (efavirenz) works like the prevention injection</li><li>• I not come to clinic when pregnant because I think I get in get in trouble from counselors</li><li>• I want a baby, I think I must stop taking efavirenz</li></ul>

			<i>when pregnant or else my baby will not be right (Group D)</i>
ADHERENCE	Studies have shown that those HIV-positive individuals taking ARVs are less likely to be fully adherent to meds if they are taking alcohol concurrently	Do not take ARVs with alcohol You cannot take your ARVs if you drink alcohol	<ul style="list-style-type: none"> <li><i>I cannot drink any alcohol at all once I have started ARVs</i></li> <li><i>I will not be given ARVs because I have had alcohol before</i></li> <li><i>As I have drunk alcohol today, I must not take my tablets today as they will not work</i></li> <li><i>One day I had alcohol, I was worried about side-effects from ARVs, but I was okay (Group D)</i></li> </ul>
CONCURRENT OIs	TB treatment defaulters have the best outcomes when on HAART (Highly active antiretroviral therapy)	Until you are adherent to TB medication, we cannot start you on ARVs	<i>I will not go to support group because I was not adherent to TB treatment and I will not be welcome (MDRTB patient Group D)</i>
	Opportunistic infections are best treated before starting ARVs to promote adherence and decrease likelihood of IRIS	We will delay starting treatment with ARVs until we have treated your other illnesses because HIV is making you vulnerable to being sick	<i>I am too sick to take ARVs. (Group D)</i>
SUPPORT GROUP	Promotion of "HIV Wellness" is vital to stay well and healthy	You are special and different for having HIV	<i>I have HIV and I am different to others. I wish I did not need the special help, I want to be normal like others (Group C)</i>
	HIV positive individuals must come to support group at least three times before he/she becomes a member	You must prove your commitment to the support group by attending at least three times before you earn the right to be a member of the programme	<i>I am working so I cannot join. And I live too far from Xora to go on a Sunday.(Group C)</i>
	Attendance at the support group is required to be a member of the Madwaleni programme		<i>They want me to stand in front of people I don't know and even people I know, and talk about things I have not told my family. (Group C)</i>
	You are stigmatised by others when living with HIV	A diagnosis of HIV is difficult to accept, but if you are committed and proactive, you can meet the challenges the virus presents in life	<i>I am disadvantaged compared to other people who are HIV negative – I am therefore dependent on additional help and support (Group C)</i>

**Table 34: Concept of communication problems in MISCONCEPTIONS theme – Groups C and D quotations**

The education and counseling is largely done by the counselors, community health workers and peer educators. As lay people, many have now had more than four years experience as counselors on the programme. They have had training on short courses (provided by government and non-governmental organizations) on such topics as adherence counseling, the HIV virus, couples counseling and many more. The messages given out to HIV positive members are well-intentioned

and largely correctly received. The transcripts revealed some subtle inconsistencies between the message given and that received, as shown above.

It is speculated that one of the reasons for this is the unbalanced dominance of the topics of ARVs and adherence within the Madwaleni HIV programme. As matters stand, there is good evidence for calling the programme the Madwaleni ARV programme, rather than the Madwaleni HIV programme. If any change is effected, however, efforts should not in any way be directed at decreasing the importance of ARVs and adherence. The balance should come in the form of boosting the issue of HIV Wellness amongst members.

The second reason for the misinterpretation concerns the consequences of task-shifting within the HIV programme. In a poorly-resourced area with few health professionals, plus the indisputable advantage of HIV positive members counseling those infected and affected by the virus, task-shifting away from the health professionals has its advantages in meeting the programme objectives. There is no denying, however, that the message loses some impact for the need to standardize across the deliverers of that message at the level of the counselors. It is necessary for the more qualified doctors and nurses to check the understanding by individuals, then to customize the message per individual requirements.

Considering the health professionals role, they must take some of the blame for poor “capturing” of non-members on to the programme. Doctors and nurses interact with non-members for no extra effort at all – people consult them for a host of different reasons related and unrelated to HIV. Of those who are untested for HIV, the opportunity to counsel on the need for an HIV test is often lost. Despite attending to a patient, his/her HIV positive status may remain unknown to the health professional. If known, the health professional often remains “Madwaleni- and clinic-centric” in their attempts to have the patient return for follow-up.

The following quotes were gathered during the GROUP D focus group, citing long distance and lack of money as logistics reasons for not attending support groups frequently:

<i>It takes me nearly an hour to walk to my nearest clinic (Soga) but I can get to Xora in a taxi when I have the money. Xora is better for me but I have no money</i>
<i>I live near the forest at Nthlonyana (close to Bomvana clinic), but I don't want to go to the support group there with all my friends</i>
<i>I am sick, and the clinic (PHC) nurse sent me to see the Madwaleni doctors. I borrowed money to go there, but now it (money) is finished</i>

**Table 35: ACCESS theme – Focus Group D quotations**

To illustrate the dangers of poor attention to the details on the part of the health professional, the following dialogues are provided; hypothetical dialogue with the exception of the actual quotes made by the GROUP D participants (same as above) when asked about the difficulties with joining the HIV programme:

Doctor:	Which is your closest clinic?
Patient replies	Soga clinic
Doctor	Ok, please attend the support group at Soga
Patient thinks	<i>It takes me nearly an hour to walk to my nearest clinic (Soga) but I can get to Xora in a taxi when I have the money. Xora is better for me but I have no money</i>
Doctor:	Where do you live?
Patient replies	Nthlonyana
Doctor	Ok please go to the support group at Bomvana (near Nthlonyana).
Patient thinks	<i>I live near the forest at Nthlonyana (close to Bomvana clinic), but I don't want to go to the support group there with all my friends</i>
Doctor:	You are not well, and I will need to review you soon. I would like to see you next week please.
Patient replies:	Yes doctor
Patient thinks	<i>I am sick, and the clinic (PHC) nurse sent me to see the Madwaleni doctors. I borrowed money to go there, but now it (money) is finished</i>

**Table 36: Concept of communication problems illustrated with actual quotes in hypothetical conversation – Group D quotations**

The first two scenarios initiated with a question asked by the health professional are much the same, but can result in the patient making a commitment he/she cannot keep – especially if the provider-patient relationship is dominated by the “busy and important doctor”, as is so often the case. A further practical problem is the misunderstandings created through the use of an interpreter. Regarding the third quote above - of all the people seen (irrespective of HIV status) who are well enough to treat as an outpatient, it is the relatively well members who could be asked to attend a future review at the more-highly resourced hospital. Notwithstanding any investigations that may not be possible at clinic level, those who are ill (but not requiring hospital admission) should be seen by health professionals at the primary health care clinic, while supported by a decentralisation strategy.

Lastly, the timing of the follow-up date in relation to the monthly date of grant payments can make a difference between successful review and lost-to-follow-up:

<i>The doctor wants to see me on the 16<sup>th</sup>, but I will go back when I have got grant money for transport</i>
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**Table 37: Date of grant concept in LOGISTICS theme – Group D quotation**



## GROUP E: DISCUSSION

### Group E: Traditional leaders – Chiefs of the Madwaleni, Mqhele, Bomvana, Soga and Melitafa communities

Themes that emerged in the chiefs' focus group were as varied as in the members' discussions. Certain of the same issues were evident, but key issues unique to the chiefs' understanding and approach emerged. The analysis falls into two main areas:

1. Ideas, challenges and suggestions surrounding the chiefs' partnering with the programme
2. The chiefs' understanding of their community members opinion of HIV and the programme

It is recognised that the current partnership with the programme is limited to an ad-hoc involvement with community issues, except for individual chiefs/headmen assisting with proof of residence documentation when required for grant applications, as well as assisting with allocation of space for VCT stations in the community when HIV testing is arranged by the programme staff in the communities.

In the eyes of the chiefs, the HIV programme has achieved a level of programme success that warrants their closer partnership tackling the challenges that HIV in the Madwaleni community presents. The existing relationship is at arm's length however; this distance and the chiefs wider view of the community at large, contribute to a mixed understanding of the operations and scope of the programme.

SUCCESS OF PROGRAMME	REACH OF PROGRAMME
<i>People they follow this programme, a person who've been there you can see the difference within a month, she become better than before.</i>	<i>I would appreciate if this programme can spread until it reaches Mthatha because people are dying and as we are black people we are too related almost all of us around Eastern Cape, a black person have a relative here and there.</i>
<i>Really it's better now than years ago, I can see to the place where I stay there is a huge difference.</i>	<i>I wish there can be a plan than we can meet with people from Mthatha and tell them about this programme or to have a health station where they send people in order to help others</i>

**Table 38: Comparison of concepts of success and reach of programme – Focus group E quotations**

Chiefs interact with a broader section of the Xhosa community, extending outside the catchment area of Mbashe sub-district. Direct acknowledgement of the success of the programme is made, but overestimates are made regarding the reach and influence of the programme. Given there are so many people who are HIV positive and have not joined the programme, the community leaders need to realise that there is much work to be done to improve the quality locally, rather than offering the same programme as far away as 1.5 hours drive away (120kms).

Were they better informed, the chiefs would be the first to concede the impracticality of people accessing the programme from too far away. Each chief will need to be thoroughly briefed on the

extent of the HIV problem in the sub-district, as well as on the structure and management of the programme itself.

### Leadership in the community

Providing traditional autocratic leadership is viewed as an important tool in achieving the programme objectives of increased membership. Any autocratic style of leadership exists however, in an imperfect harmony with the agreement on wide and extensive consultation, in acknowledgement of the ethical importance of recognising autonomy and self-determination in individuals and communities.

TRADITIONAL AUTOCRATIC LEADERSHIP	RECOGNISING AUTONOMY
<i>You must have a list whereby you check their dates, and if she/he does not pitch the chief must be contacted and told about this.</i>	<i>We can have these meetings in our locations or in clinics, we need to give people a chance to express their feelings and come up with their views.</i>
<i>I would love to suggest that if there is someone HIV positive and do not attend the support group, the chief responsible to that location must take further actions about that.</i>	<i>I would like to suggest that we must have representatives from our locations that will work together with the chiefs and help on how to treat the old people to young ones.</i>
<i>I will appreciate if we can give the chief all the details of people who are positive. It must be chief's responsibility, they must do follow up everytime, they must attend support groups in order to get treatment and they will be helped.</i>	<i>We also need to talk to those people we elected in our location to assist the office about these groups and help those people who are afraid to go there.</i>

**Table 39: Comparison of concepts of autocratic leadership and recognising autonomy – Focus group E quotations**

The need for a middle ground is clearly evident. Both viewpoints cannot be the single voice of the community leadership in tackling the problem of HIV positive individuals not joining and/or attending the programme. Middle grounds comments are deemed to be compromises of both extremes; each potentially the catalyst for practical ways forward for its appeal on both sides of the spectrum.

### Liaison with the HIV Programme Management

Liaison with the programme staff on strategy and implementation is welcomed by the chiefs; this opportunity for a closer working relationship is currently recognised as being under-utilised. It is the success, whether deserved or not, that has made the programme worthwhile in the eyes of the chiefs; they are now happy and enthusiastic to pursue goals and objectives in collaboration with the programme management.

<i>I would love the experts to help us about how to deal about this, how can we approach them and advice them even about who to prevent this.</i>
<i>If government can give mandate to the chiefs to make sure that a person who is HIV positive must go to the health station in order to get help.</i>
<i>We are also trying to help the doctors and the hospital to preach all these things. This is the only thing that hinders them (HIV positive members)</i>
<i>I did not study about her disease, he/she knows that I do not have a doctorial profession nor nursing, so I am not interested to her disease, the only thing they mention is that this person must be at hospital the doctor want to see her/him.</i>

**Table 40: Respect for HCWs concept in PARTNERING THE PROGRAMME theme - Focus group E quotations**

Each of the comments categorised above as the “middle ground” involves liaison and respectful cooperation with the health professional workers (HPWs) and government (Department of Health). Encouragingly for the staff members, the chiefs themselves are advocating the closer association, perhaps in acknowledgement of this initiative taken by the programme management. By having closer cooperation, important advantages are gained: HPWs will gain greater access to more HIV positive individuals, the stigma of association with HIV that health workers (including counselors) carry is diluted by a joint approach with the local chiefs, and for liaising with “experts” in the HIV field, neither the authority nor the mandate of the chiefs to act is compromised or exceeded respectively.

The quotations above can be interpreted as statements of compromise on their authoritarian stance. Importantly, all the quotations are linked by a common thread: interaction with the health professionals.

#### Relationship with the Department of Health as government

The chiefs experience of the ways of the Department of Health’s handling of other opportunistic health problems influenced the suggested plan for HIV management. Experience of actively locating patients in the community known to be infected with multi-drug resistant tuberculosis (MDRTB) has influenced the chiefs to believe the same proactive “case-finding” can apply to management of the HIV epidemic in this region.

<i>ok-at Bomvana the nurses did it, they tested someone and find out he has got TB, the dangerous one and they transfer her/him to the hospital because she did not want to accept that he/she has got it. You must have a list whereby you check their dates, and if she/he does not pitch the chief must be contacted and told about this. The chief will send someone to this patient and take her/him to hospital or to support group and that where she/he can explain why he/she does not pitch. I think this is an easy way.</i>
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**Table 41: Patient autonomy and autocratic leadership concepts in PARTNERING THE PROGRAMME theme – Focus group E quotations**

In contrast, there exists an undercurrent of dissatisfaction with government amongst the chiefs. They are of the opinion that blame for ongoing stigma and non-disclosure can be placed at the door of government. Unfortunately, these sentiments could not be further explored, but it is assumed that they

believe the government's efforts to promote autonomy, confidentiality and the right of individuals put paid to more justice on a community level, namely by routine testing and open disclosure of HIV.

<i>They are supposed to attend support group but they are not honest, and they do not know who infected who. This is the only problem. That is why I said the government is encouraging this thing.</i>
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<i>Eh---this thing of not telling the truth is very bad. I think its encouraged by the government on the other side.</i>
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**Table 42: Government concept in PARTNERING THE PROGRAMME theme – Focus group E quotations**

### Chiefs understanding of the opinions and concerns of community members about HIV and the programme

A common feel for the community perceptions is the key area on which the chiefs and the programme management team need to have agreement. Their sense of the problems around community perceptions of HIV is in keeping with that established in the analysis of the other focus groups during this research exercise.

### **DISCUSSION: THEME 10.**

### **ENCOURAGING JOINING AND ATTENDANCE / BEST SYSTEMS AND STRUCTURE**

The research question as to why HIV positive members do or do not join the HIV programme, this theme JOIN AND ATTEND serves as a summary to bring together the findings from each of the focus groups.

Presentation of the analysis of this theme in the focus group A and B results section highlighted many factors predominantly reflect demands on the programme, as seen from the perspective and experience of the HIV positive individual. The initial choice of themes was one out of three options, of which the “Ten Theme” option was chosen to qualitatively best capture the issues raised in the focus group A and B.

Consideration of one of the other ways of categorizing the concepts into themes recognised the importance of member demands versus service supply issues: the individual aspects of a three-stage assessment of a patient manifest as this member demand. It is remarkable to think that traditionally many clinicians have paid little attention to the individual and contextual aspects of patient consultation and care, in light of the myriad of links and associations that have been highlighted in this research exercise.

The third rationale for grouping concepts into themes had the same distinction between demand and supply factors at its heart: grouping concepts into three different broad themes concerning the psycho-social needs of the members/non-members (demand), the knowledge-based facts around HIV

and the disease it causes, as well as those concepts depicting the systems within the HIV programme (supply).

The chosen method of ten themes provided for more themes and, therefore, a more detailed analysis. The links in the ten themes as described in results and analysis of focus groups A and B have pinpointed those factors which will help or hinder HIV positive individuals to join the programme. The focus has, therefore, remained from the member perspective. This results section highlighted the positive, negative, and neutral associations of concepts with the general theme of JOIN AND ATTEND, especially with respect to focus groups A and B participants.

There is some logic to the assertion that those concepts that were uppermost in the minds of focus group participants, with respect to their opinion about the programme, will be the most grounded of the concepts. Alternatively, there are some subjects that impact a wide range of issues relating to the programme; these manifest in concepts with the highest densities. Accordingly, all associations with the highest ranked concepts and themes for both groundedness (10) and density (10) in each of the focus groups are tabulated below, as the combined rankings of the “top” concepts and themes identified:

CONCEPT/THEME	(G,D)	TOP 10 “G” RANKING	TOP 10 “D” RANKING
ACCESS	(23,10)	6	4
Adherence	(20,11)	7	3
ARVS	(53,3)	1	-
Child	(16,6)	10	9
Community perceptions	(3,7)	-	6
COURSE OF DISEASE	(12,7)	-	6
Hand-to-mouth	(19,7)	8	6
FAMILY	(18,3)	9	-
<b>JOIN AND ATTEND</b>	<b>(27,15)</b>	<b>3</b>	<b>1</b>
MUTUAL SUPPORT	(53,15)	1	1
STATUS ACCEPTANCE	(24,9)	4	5
Test	(25,3)	5	-
Virus	(7,6)	-	9
Waiting time	(18,1)	9	-

Table 43: Top ranked concepts in JOIN AND ATTEND theme by groundedness and density

ASSOCIATION OF THEME AND RELEVANT SUB-THEME	ENCOURAGING JOINING AND ATTENDANCE
A culture of strong adherence grows the impact of antiretrovirals	

Taking the test is the first step to knowing the virus	Helps
Strong bonding and knowledge help in providing mutual support within the support group, but are of little impact elsewhere	Neutral
Living a hand-to-mouth existence hinders redefining of dependencies	
Religious faith helps with the right lifestyle choices	
Preoccupation with illness over an understanding of HIV Wellness hinders increasing the awareness of the course of disease	Hinders
Paternal dominance hinders realisation of the importance of the family unit	
Poor community perceptions hinders self-acceptance and understanding of an HIV positive status	
Unavailability of transport hinders improving access to care	

**Table 44: Association between sub-themes/themes and JOIN AND ATTEND theme**

Within the JOIN AND ATTEND theme, it is important to re-visit the supply issues. The concepts assigned to the JOIN AND ATTEND theme represent the supply side of the programme: services that are provided to meet the member demands and expectations: member follow-up, home visit, split support group (split SG), clinical support, counseling, staff confidentiality, waiting time, queue and one-stop-shop. Each of these is related to the programme systems and structures that may be modified to meet the requirements of the members, both current and prospective. It is, therefore, not only whether these system elements help or hinder individuals join the programme, but also whether the service meets the members' expectations.

Members approve of the idea of the programme being a one-stop shop. They agree with the idea of multiple support groups (notwithstanding resources). Member-follow-up is appreciated, as is the practice of home visits. Changes are necessary to decrease waiting times and queuing, as well as varying the use of the white car in the community. Improvements to clinical support and individual counseling will increase appreciation of these services, rather than both being undervalued and taken for granted. Health care professionals will themselves have to be canvassed on the changes to the HIV staff programme, which features little in this debate.

## RECOMMENDATIONS

### TARGETING SPECIFIC PROBLEMS WITH ACCESS TO CARE AND STIGMA

Generally there are “helpers” and “hindrances” affecting numbers joining and regularly attending the programme. The “helpers” that need attention are those that are poorly-grounded in the transcripts. Conversely, the “hindrances” that need attention are notable for being highly grounded. There is a possibility that some concepts requiring attention may more rapidly be handled without disruption to other concepts if they are associated with a low density in the analysis.

TARGET HINDRANCES	TARGET HELPERS
lack of money (10)	HIV Wellness (10)
child (16)	Parental control (4)
male (18)	Staff confidentiality (2)
stigma (18)	Religious faith (1)
waiting times (18)	Safe sex (1)
hand-to-mouth (19)	
access (23)	

**Table 45: Targeting concepts for attention – Recommendations**

There are a few organizations in the community that can be enlisted to drive the importance of HIV testing and joining the programme. Parents can be targeted indirectly and directly through their children’s attendance at schools. The local backpacker Bulungula has significant community ownership and participation. The old-style but popular Haven Hotel is an important community link, as well as the small, but growing, center for the mentally disabled, namely Ikhaya Luxolo.

### DEBATE THE MERITS OF THE VOLUNTARY COUNSELING AND TESTING IN ITS CURRENT FORM

Overview of the quality of pre- and post-test counseling conducted before and after the testing for HIV. Under the current system, this is the first “point of sale” for impressing on newly-diagnosed HIV positive individuals the importance of joining the HIV programme.

An audit tool needs to be developed to evaluate the quality of the VCT process at the health institutions and the hospital. This can be achieved on two levels. Firstly, through evaluation of the VCT process itself at the time and point of testing, irrespective of whether the individuals tested HIV positive or negative. Cognisance must be taken of the little merit in making any concrete in-depth plans with an individual shortly after being told of an HIV positive diagnosis. The focus, therefore, can fall on a “contract” being agreed upon between the individual and the counselor to have a follow-up. Telephonic follow-up must be agreed upon, as well as encouraging attendance at the support group.

It has also been proposed that a pamphlet with bullet points listing information (in Xhosa) after either an HIV positive or HIV negative diagnosis can be provided at the time of VCT. This will require more rigorous testing and evaluation prior to implementation.

Secondly, interviewing HIV programme members as to their experience of the VCT process will, by implication, retrospectively provide an understanding of whether the VCT goal in managing HIV positive clients has been met. These goals center on the clear objective of having a newly-diagnosed HIV positive individual joining the HIV programme early in the course of his/her disease. Practically, a target conversion rate from “VCT positive to members” must be agreed upon, plus a decision as to the preferred maximum time between testing and joining the programme. The periods of evaluation must overlap for more accurate monitoring of the trend over time.

#### IMPROVE REGISTRATION OF THOSE TESTED HIV POSITIVE AT ALL VCT STATIONS

Knowing who is tested when, plus keeping records of contact details is invaluable for programme monitoring and evaluation. This practice is currently done well at the “VCT outreach” by the HIV programme staff, and antenatal records hold details of the pregnant women tested (except contact details), but records need to be extended to the VCT stations at the health facilities, both in-patient and out-patient. There is the possibility that individuals knowing their details will be recorded will be discouraged from testing. Proper transparency and informed consent at the pre-test counseling stage will allay some fears, and a balance between patient autonomy and the need for more HIV testing of the community at large must be debated.

#### PROACTIVE IDENTIFICATION OF VULNERABLE CHILDREN

Children were specifically excluded from participation in the focus groups. The well-being of their children, however, was an obvious concern amongst participants (a highly-grounded concept). The recommendation is that children of HIV positive adults are identified when testing is done at VCT outreach. These children meet the definition of “vulnerable child” whether themselves known as HIV positive or not. With agreement of the parent/caregiver, the VCT team will capture details of these children on the database. They will then be followed up within the Orphans and Vulnerable Children (OVC) programme.

#### WITHDRAWAL OF MANDATORY SUPPORT GROUP MEMBERSHIP AS CRITERIA FOR ACCESS TO THE HIV PROGRAMME

It is recommended that those individuals who do not wish to attend the support group will not be required to do so. More will join, more will be lost to follow-up on Wellness and ARVs but the responsibility for any decision and/or circumstances leading to poor attendance and inadequate partner-provider teamwork will lie with the member, not with the programme in the form of barriers to entry. While stricter rules regarding dispensing of medication being conditional on consistent



attendance and adherence to all medications can apply, such measures are ethically sound only in specific cases. With the advent of antiretrovirals and the accompanying deluge of information concerning resistance, health professionals were quick to judge patients critically and wrongly withhold treatment, using the often-quoted excuse of “in their own best interests”. Local committees set up to evaluate eligibility for antiretrovirals now seem excessive. To maintain the importance of adherence in counseling patients, while promoting HIV Wellness is suggested as a preferable balance.

That support group attendance can be a barrier to entry for those patients eligible for antiretrovirals is also evident. There are a small, select number of patients who are started on antiretrovirals as in-patients by doctor discretion only. These are called Group 1 patients, started without the input It is recommended that there be a group called Group 1 Access patients that are started on ARVs by senior clinicians (at the initiation either senior clinical or non-clinical HIV management staff). These patients are those who meet the criteria for starting ARVs by their adequate disclosure to family members, understanding of HIV and antiretrovirals, suitability on clinical examination and high likelihood to have good adherence. It is recommended these patients be entered on the database and started on antiretrovirals at the earliest opportunity irrespective of their formal records of support group attendance and/or adherence checks by pill count.

#### STREAMLINING THE SUPPORT GROUP TO FOCUS PRIMARILY ON NEW ATTENDEES NEEDING HELP WITH SELF-ACCEPTANCE OF THEIR HIV POSITIVE STATUS

The support groups (especially Madwaleni) are currently bloated with too many individuals, too many didactic lecture-listen education sessions that are a poor imitation of proper facilitated psychosocial support, and host a mix of individuals whose needs are too diverse to meet all in one group. It is proposed that the focus of the support group be on new members looking to learn about their HIV status.

#### INTRODUCING HEALTH PROGRAMMES AND INCOME GENERATION PROJECTS (RUN AND ORGANISED BY VOLUNTEERS AND STAFF MEMBERS) DOUBLING AS HIV SUPPORT FORUMS FOR THE “VETERAN” HIV POSITIVE INDIVIDUALS

The hospital management is to identify a pilot health programme for implementation on its own merits and value independently of any association with HIV. Examples of such programmes include Early Childhood Development and/or Tuberculosis Awareness and Education Programme. It is recommended that community members are to volunteer on these programmes with the incentive of possible selection for training and accreditation as trainers in that field. These volunteers will then be eligible for application to stipended “posts” funded by government and non-governmental departments within these programmes. HIV status will not be relevant criteria for selection, but counseling and education on HIV Wellness will be included in all training forums. Aimed at both the participants and

the volunteer trainers, the HIV education will take place in a forum that is not defined for being a group of HIV –positive individuals.

Training on income-generation and health groups can be funded and accredited by leading corporate businesses, as well as the South African Qualifications Authority (SAQA).

#### USING THE HIV SUPPORT GROUP – TRAINING GROUP SYSTEM AS A TWO-WAY FEEDER SYSTEM

After a set number of weeks attendance in the HIV support group, an HIV-positive individual can leave to join a training group. A proportion can be kept on to teach incomers to the support group, and a further proportion will leave the group, but continue to receive medication and counseling monthly. A proportion will however join the health/income programmes described above, initially as a volunteer.

Similarly, it is recommended that VCT will be encouraged for anybody in the programmes, as well as regular HIV education counseling sessions being encouraged. It is hoped that the HIV positive members will play a large part in creating the appropriate environment and support for participants agreeing to take an HIV test.

#### INTEGRATING THE HIV CLINIC INTO OUTPATIENTS CLINIC

It is proposed that the push continues for established HIV programme members to be consulted clinically in the general outpatients department, rather than the HIV department. This applies in particular to the collection and dispensing of medication in the form of antiretrovirals and other concurrent medication.

#### DEVELOPMENT OF PHARMACY ASSISTANTS AS HIV COUNSELORS

It is recognized that the point of dispensing is an under-utilised patient-provided contact session, with respect to education and counseling. Capacitating these individuals primarily through the Basic And Post-Basic Pharmacy Assistant Training Courses will not focus only on counseling HIV-positive individuals on adherence and related HIV issues, but will focus more broadly on chronic disease management in general.

#### TRADITIONAL LEADERS FORUMS

Regular reporting sessions should be held with the chiefs of the area for mutual sharing of ideas and challenges.

## TRADITIONAL HEALERS FORUMS

Despite the lack of reference to the traditional healers in the focus groups, their absence from the discussion is a real concern rather than support for their perceived irrelevance. They are anything but irrelevant, and conscious efforts need to be employed to partner traditional healers in an effort to have more people access the HIV programme – through or by their involvement.

## ESTABLISH FORMAL REFERRAL SYSTEMS BETWEEN THE MAIN EMPLOYERS IN GAUTENG AND THE HIV WELLNESS PROGRAMMES IN THE “OLD TRANSKEI”

An approach must be made to employers of migrant labourers in other provinces (mostly mining companies in Gauteng) regarding the medical boarding of their employees. They need to be strongly encouraged to arrange the official, direct transfer of an individual from an employee wellness programme to a specific wellness programme in the Eastern Cape. This transfer must be as seamless as possible.

## STRATEGISING A WAY FORWARD IN PROACTIVELY MINIMISING THE HEALTH IMPACTS OF THE MIGRANT LABOUR SYSTEM ON THE FAMILIES IN THE MADWALENI REGION

To understand the numbers of families affected, an audit of those HIV members whose family unit is fractured for men leaving to work elsewhere (predominantly mines), should be conducted. If the numbers are substantial, then it can be decided which is the correct channel to minimize the disruptive social, psychological and clinical health effects of the fractured families. Decisions must be taken as to whether the Department of Health is the appropriate body, as well as taking cognizance of the stigmatization and singling-out of HIV-positive individuals. It may be that the problem can be identified within the context of HIV at Madwaleni (especially with the usefulness of the extensive member database), but tackled from a more general community health perspective by the relevant authorities in discussion with employers.

## INCIDENTAL MODIFICATIONS OF FORM

- The “date of death” filed on the form in the HIV Wellness files is to be deleted.
- Include genogram on the form to capture other family members’ existence and whereabouts (e.g. at home, working on mines). Replaces “children” category on front page of demographic details.
- Include place for World Health Organisation HIV Staging to be noted at each clinical visit (helps build awareness of HIV Wellness continuum) as opposed to CD4.

## STRATEGY TO REDEFINE DEPENDENCY FACTORS

In an attempt to streamline the application for disability and other grants, doctors will need to apply the eligibility criteria more strictly. Improvement in access to Grant in Aid and social assistance (food parcels) will compensate for those ineligible on the grounds of insufficient medical impairment alone. It is hoped the arrival of three/four social workers later in 2009 will capacitate the team of Madwaleni multidisciplinary health professionals to achieve this goal.

Income generation projects should be the unifying factor in a support group coming together for reasons unrelated to an HIV status.

## TRAINING OF STAFF

In addition to the training programmes proposed above, it is recognized that there are current deficiencies either in the knowledge of counselors, or the frequency of educating members, on such topics as

- HIV and AIDS and the distinction between them
- HIV Wellness and its importance

It is recommended that consideration be given to the development of “specialist counselors” in certain fields. They will not only be given training on knowledge but deal with the relevant patients/members on a regular basis.

- TB and HIV,
- Couple counseling
- Prevention of Mother to Child Transmission (PMTCT)
- Early Childhood Development

It is proposed that the merits of this specialization be debated with the objective of decreasing misconceptions arising from over-standardization of the information passed from health professionals to lay counselors.

It is recommended that training of health professionals occurs: specifically in appropriate counseling of patients after an outpatient consultation or an in-patient stay. The objective must be to emphasize the importance of follow-up plus to facilitate the practicality of doing so as well as possible.

## SUPPORT FOR STAFF

It is proposed that debriefing/feedback/support sessions be properly scheduled, as well as clinical review – irrespective of whether a health complaint is present - for all programme staff six-monthly.

## COMMUNITY AWARENESS AND UNDERSTANDING

Introduction of community awareness and education sessions around HIV/AIDS that take place independently of support groups and/or VCT outreach days

## STRENGTHENING OF HOSPITAL DOWN-REFERRAL SYSTEM OUTSIDE OF HIV PROGRAMME

It is suggested to discourage the natural tendency for hospital-based health professionals to keep the more seriously ill out-patients close at hand by requesting follow-up at the hospital. The principle of having the well patients come from afar more infrequently, whereas the ill are seen at their clinics on down-referral days must be encouraged.

The proposed “doctor per clinic” allocation for a bimonthly clinic visit is intended to grow the doctor’s understanding of the community in which he/she works, plus strengthen the hospital-clinic teamwork.

## INTRODUCTION OF MORE COUNSELING TOOLS TO PROMOTE STATUS ACCEPTANCE

It is recommended that a drawn timeline is kept in the patient’s file. This is used in counseling to depict key “health events” before and after dates of key interventions such as testing for HIV and attendance at the first support group. It is hoped the benefits of these interventions will be evident by the fewer adverse health events occurring after these interventions. Use of evidence-based counseling tools to modify behavior is now recommended (for example a graphical tool depicting the importance of change versus ease of doing so).

Nationally the focus is on increasing the minimum CD4 level at which an individual should be prescribed antiretrovirals. This is motivated by improved morbidity and mortality data. Additional indicators of percentage of screening for preventable conditions (cervical cancer, pneumocystis carinii pneumonia and tuberculosis) are being used more often recently. This needs to extend to such useful indicators as:

- period between HIV positive diagnosis and first support group attendance
- conversion rate of VCT positive on to programme (target % over an agreed period of time)
- time between ARVs eligibility (according to CD4) and ARV starting date (each patient)
- percentage on ARVs of programme members
- percentage starting ARVs below CD4 50

## CREATIVE USE OF STIPENDING LAY PERSONS

With the proposed establishment of additional programmes, it is suggested that the use of a reward system to reinforce initial attendance may be useful. Training projects, food garden, looking after young children, tracking patient defaulters are all examples of projects that need the initial impetus before the benefits of involvement are well-understood and appreciated by the participants for their early experience. The current Madwaleni practice of paying stipends and monetary incentives to staff members to do additional tasks is not too dissimilar. The practice could be extended to non-members of the programme, since criteria for joining are not HIV-related. Payment of stipends is self-limiting in the income-generation groups.

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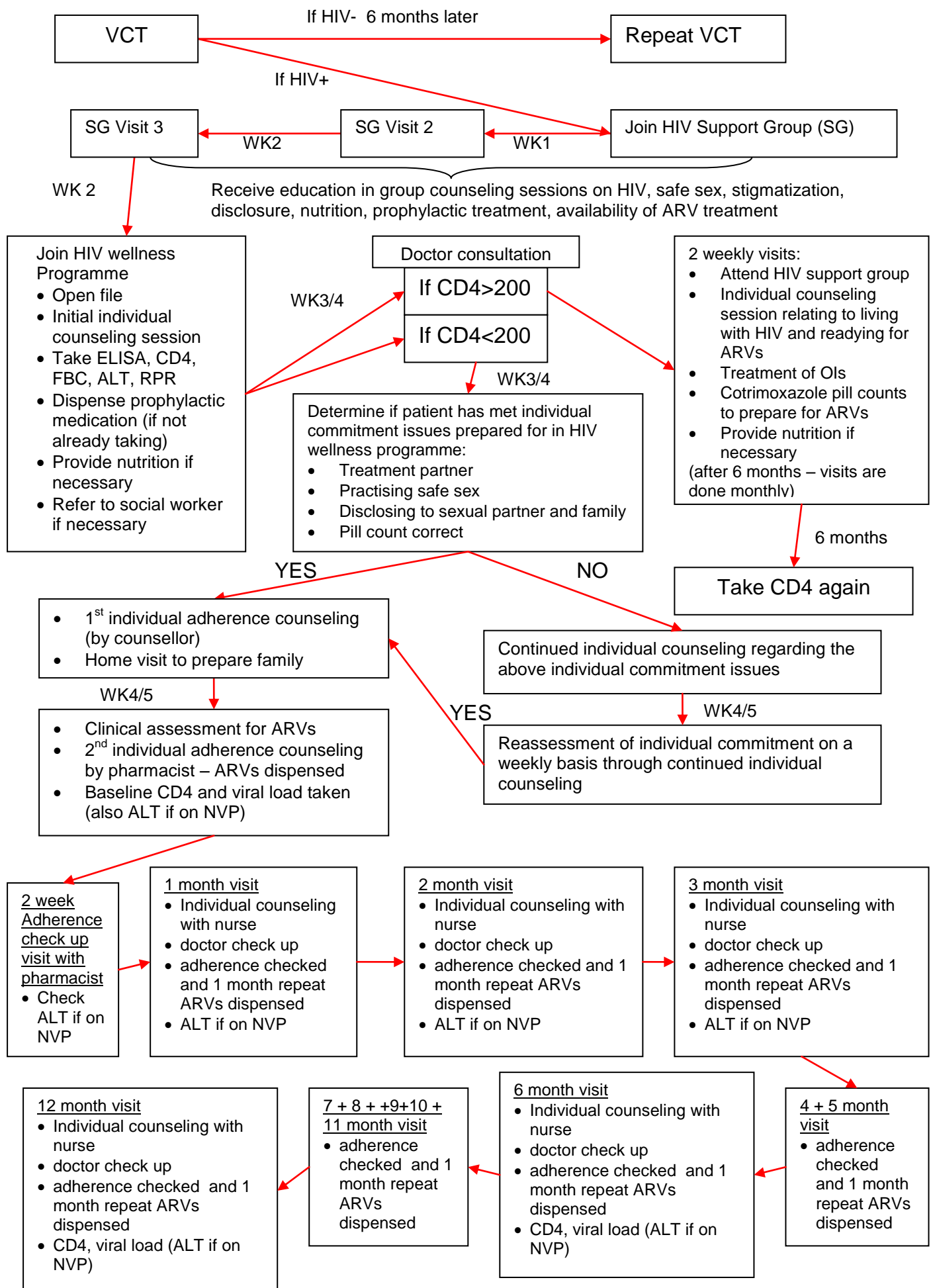
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## APPENDIX 1 JOINING AND ATTENDING HIV WELLNESS PROGRAMME



## APPENDIX 2 HIV WELLNESS PROGRAMME - MEMBER FILE

	Visit date	Visit date	Visit date	Visit date
Insert date				
Visit number	1	2	3	4
Weight (in kg)				
Loss in weight >3kg since last visit (Y/N)?				
TB symptoms? (Y/N)				
Using family planning? (Y/N/NA) (excl. condoms)				
Used condoms since last visit? (Y/N/NA)				
Are you currently pregnant? (Y/N/NA)				
If pregnant, PMTCT done? (Y/N)				
Made disclosure to partner? (Y/N/NA)				
Made disclosure to children? (Y/N/NA)				
Made disclosure to others? (Y/N/NA)				
Are you taking any Xhosa medicine? (Y/N)				
<b>Nutrition</b>				
Are you eating a balanced diet (Y/N) 				
Given nutritional supplements at this visit? (Y/N)				
Drink alcohol frequently (Y/N)?				
<b>Disability grants</b>				
Getting a disability grant? (Not eligible (NE), Not applied (NA), Waiting (W), Received (R))				
If not and qualifies, referred to social worker? (Y/N)				
<b>Cotrimoxazole (bactrim)</b>				
Bactrim pill count correct? (Y/N/NA)				
Number of Bactrim pills given at this visit?				
If not using bactrim due to stage1 (WHO1) or Dr decision (DD)?				
<b>Referred to a hospital since last visit? (Y/N)</b>				
If so, Madwaleni (M), NMH (N), Other (O)				
Days in hospital				
Diagnosis at admission				
<b>Concurrent TB? (Y/N)</b>				
New case (NC), Retreatment (RT), Failure (RF), Interruption (RI)				
Adherent to TB Rx? (Y/N)				
Intensive(I)/Continuation(C) phase				
Number of Months				
AFB positive (Y/N/Not taken (NT))				
TB culture (Y/N/Pending(P))				
TB sensitivity test done (Y/N)				
<b>Investigations</b>				
CD4 (per uL)				
CD4%				
Viral load (c/ml)				
Haemoglobin (g/dl)				
Platelets (x10 <sup>9</sup> per litre)				
ALT (U/L)				
RPR (titre ratio)				
Pap smear				
Other labs/ix				
Other labs/ix				

<b>Vital signs</b>				
Blood pressure (BP)				
Pulse rate				
Temperature				
<b>Stage (1/2/3/4)</b>				
<b>Opportunistic infection (clinical)</b> (Not applicable(-), New (N), Recurrent (R), Ongoing (O))				
oral herpes (-/N/R/O)				
acute shingles (-/N/R/O)				
weightloss >10% (-/N/R/O)				
unexplained pyrexia > 1/12 (-/N/R/O)				
unexplained diarrhoea > 1/12 (-/N/R/O)				
oral hairy leucoplakia (-/N/R/O)				
oral thrush (-/N/R/O)				
vaginal thrush 1/12 (-/N/R/O)				
vaginal herpes (-/N/R/O)				
oesophagus thrush (-/N/R/O)				
PPE				
performance status				
LRTI				
lymph node for FNA? (Y/N)				
CNS clinically normal? (Y/N)				
severe bact infection (-/N/R/O)				
pulmonary TB (-/N/R/O)				
ex pulmonary TB (-/N/R/O)				
Other				
<b>Selected for ARV treatment? (Y/N)</b>				
<b>If not, dr review date</b>				
<b>Date of next visit</b>				
<b>Name of nurse/doctor/other</b>				
<b>Medical notes:</b>				

## **APPENDIX 3**

## **PARTICIPANT INFORMATION LEAFLET AND CONSENT FORM**

### **TITLE OF THE RESEARCH PROJECT**

*Laying the foundations to restructure the Madwaleni HIV Wellness Programme using knowledge of the community perceptions of the programme in relation to their needs and priorities while living with HIV.*

**PRINCIPAL INVESTIGATOR:** Dr Richard Cooke  
**ADDRESS** Madwaleni Hospital, Elliotdale, Eastern Cape  
**CONTACT NUMBER:** 084 240 3857

You are being invited to take part in a research project. Please take some time to read the information presented here, which will explain the details of this project. Please ask the staff conducting the study or the doctor any questions about any part of this project that you do not fully understand. It is very important that you are fully satisfied that you clearly understand what this research entails and how you could be involved. Also, your participation is **entirely voluntary** and you are free to decline to participate. If you say no, this will not affect you negatively in any way whatsoever. You are also free to withdraw from the study at any point, even if you do agree to take part.

This study has been approved by an ethics committee of Stellenbosch University.

### **What is this research study all about?**

- This study will be conducted at Madwaleni and surrounding clinics.
- The study aims to explore your perceptions, understanding and priorities concerning living with HIV so as to restructure and improve the HIV Wellness programme to cater for these needs.
- Focus group discussions will be conducted with both support group members and HIV positive non-members in the community.

### **Why have you been invited to participate?**

- As an HIV positive member of the community, it is assumed you have valuable opinions as to the content and worth of the Madwaleni HIV Wellness Programme and the researcher would appreciate it if you could share this knowledge.

### **What will your responsibilities be?**

- To share to the best of your ability your understanding of the Madwaleni HIV Wellness Programme, and its strengths and weaknesses.



**Who will benefit from your taking part in this research?**

- The HIV programme members to benefit from an improved service which is structured to meet their needs and expectations.;
- HIV positive non-members who may feel obliged to take part in an improved programme more suited to their needs

**Are there in risks involved in your taking part in this research?**

- No risks are involved when you participate in this research.

**Who will have access to information collected in this study?**

- Information collected will be treated as confidential and protected. If it is used in a publication or thesis, the identity of the participant will remain anonymous.

**What will happen in the unlikely event of some form injury occurring as a direct result of your taking part in this research study?**

- There is no risk of injury involved in participating in this study.

**Will you be paid to take part in this study and are there any costs involved?**

- No, you will not be paid to take part in the study, but your transport and meal costs will be covered for each study visit outside the normal support group visits. There will be no costs for you personally, if you do take part.

**Contact details**

- You can contact Dr Richard Cooke at telephone 084 240 3857, or in person at the hospital if you have any further queries or encounter any problems.
- You will receive a copy of this information and consent form for your own records.

### Declaration by participant

By signing below, I (*name*) ..... agree to take part in a research study entitled

***Laying the foundations to restructure the Madwaleni HIV Wellness Programme using knowledge of the community perceptions of the programme in relation to their needs and priorities while living with HIV.***

I declare that:

- I have read or had someone read to me this information and consent form and it is written in a language with which I am fluent and comfortable.
- I have had a chance to ask questions and all my questions have been adequately answered.
- I understand that taking part in this study is **voluntary** and I have not been pressurised to take part.
- I may choose to leave the study at any time and will not be penalised or prejudiced in any way.
- I may be asked to leave the study before it has finished, if the researcher feels it is in my best interests, or if I do not follow the study plan, as agreed to.

Signed at (*place*) ..... on (*date*) ..... 2008.

**Signature of participant**

**Signature of witness**

## **APPENDIX 4**

### **DECLARATION BY INVESTIGATOR INFORMED CONSENT**

I (*name*) ..... declare that:

- I explained the information in this document to (*name*) .....
- I encouraged him/her to ask questions and took adequate time to answer these questions.
- I am satisfied that he/she adequately understands all aspects of the research, as discussed above.
- I did not use a translator.

Signed at (*place*) ..... on (*date*) ..... 2008.

**Signature of investigator**

**Signature of witness**

## **APPENDIX 5**

## **DECLARATION BY INTERPRETER**

I (*name*) ..... declare that:

- I assisted the investigator (*name*) ..... to explain the information in this document to (*name of participant*) ..... using the language medium of Xhosa.
- We encouraged him/her to ask questions and took adequate time to answer them.
- I conveyed a factually correct version of what was related to me.
- I am satisfied that the participant fully understands the content of this informed consent document and has had all his/her question satisfactorily answered.

Signed at (*place*) ..... on (*date*) ..... 2008.

.....  
**Signature of interpreter**

.....  
**Signature of witness**

## **APPENDIX 6**

## **SAMPLE RECORD OF CONCEPT ASSOCIATIONS**

HU: MastersFocusGroups

File: [C:\Users\Richard\Documents\Scientific Software\ATLAS\TextBank\MastersFocusGroups.hpr6]

Edited by: Super

Date/Time: 06/09/09 21:50:53

-----  
Concept

Concept Filter: All [73]  
-----

white car

<is part of> community perceptions

<is associated with> home visit

<contradicts> transport

stigma <is associated with>

waiting time

<contradicts> ACCESS

<is part of> JOIN AND ATTEND

VIRUS

adherence <is associated with>

AIDS <contradicts>

cure <is part of>

HIV <is part of>

knowledge <is associated with>

test <is associated with>

transport

<is cause of> ACCESS

white car <contradicts>

transmission

test

<is cause of> STATUS ACCEPTANCE

<is associated with> VIRUS

COURSE OF DISEASE <is associated with>

stigma

<is part of> community perceptions

<contradicts> disclosure

<is associated with> white car

STATUS ACCEPTANCE

<contradicts> JOIN AND ATTEND

<contradicts> paternal dominance

community perceptions <contradicts>

COURSE OF DISEASE <contradicts>

disclosure <is part of>

hand-to-mouth <contradicts>

male <contradicts>

MUTUAL SUPPORT <is cause of>

test <is cause of>

staff confidentiality

<is part of> JOIN AND ATTEND

split SG

<is cause of> JOIN AND ATTEND  
adherence <is cause of>  
elderly <is cause of>

smoking  
<contradicts> adherence  
<is part of> LIFESTYLE CHOICES

side effects  
<is part of> ARVS  
adherence <is associated with>

self-respect  
<is part of> MUTUAL SUPPORT

scary  
<is part of> community perceptions  
<is associated with> making excuses

safe sex  
<is part of> LIFESTYLE CHOICES

respect  
<is part of> MUTUAL SUPPORT

religious faith  
<is part of> LIFESTYLE CHOICES

queue  
<contradicts> ACCESS  
<is part of> JOIN AND ATTEND

PMTCT  
child <is associated with>

paternal dominance  
<is associated with> child  
<is part of> FAMILY  
<is associated with> male  
<is associated with> marriage  
MUTUAL SUPPORT <contradicts>  
STATUS ACCEPTANCE <contradicts>

parental control  
<is associated with> child

one-stop shop  
<is cause of> ACCESS  
<is part of> JOIN AND ATTEND

OIs  
<is part of> COURSE OF DISEASE

normality  
<is associated with> free of stress  
disclosure <is cause of>

MUTUAL SUPPORT  
<is associated with> JOIN AND ATTEND  
<contradicts> paternal dominance  
<is cause of> STATUS ACCEPTANCE

advice <is part of>  
bonding <is part of>  
choice <is part of>  
comfort <is part of>  
DEPENDENCY <is cause of>  
discipline <is part of>  
education <is part of>  
hope <is part of>  
isolation <contradicts>  
knowledge <is part of>  
respect <is part of>  
self-respect <is part of>

member follow-up  
<is part of> JOIN AND ATTEND  
adherence <is cause of>

marriage

paternal dominance <is associated with>

male  
<is associated with> community perceptions  
<is associated with> denial  
<contradicts> STATUS ACCEPTANCE  
paternal dominance <is associated with>

making excuses  
<is part of> community perceptions  
<is associated with> denial  
scary <is associated with>

LIFESTYLE CHOICES

alcohol <is part of>  
choice <is associated with>

religious faith <is part of>  
safe sex <is part of>  
smoking <is part of>

lack of money  
<contradicts> ACCESS  
<is associated with> hand-to-mouth

knowledge  
<is associated with> ACCESS  
<is part of> MUTUAL SUPPORT  
<is associated with> VIRUS  
adherence <is associated with>

JOIN AND ATTEND

<contradicts> ACCESS  
ARVS <is cause of>  
clinical support <is part of>  
counselling <is part of>  
COURSE OF DISEASE <contradicts>  
employment <contradicts>  
home visit <is part of>  
income generation <is cause of>  
member follow-up <is part of>  
MUTUAL SUPPORT <is associated with>

one-stop shop <is part of>  
queue <is part of>

split SG <is cause of>  
staff confidentiality <is part of>  
STATUS ACCEPTANCE <contradicts>  
waiting time <is part of>

isolation  
<contradicts> MUTUAL SUPPORT

income generation  
<contradicts> DEPENDENCY  
<contradicts> hand-to-mouth  
<is cause of> JOIN AND ATTEND  
employment <is cause of>

illness  
<is associated with> ACCESS  
<is associated with> clinical support  
<is part of> COURSE OF DISEASE

hunger

hope  
<is part of> MUTUAL SUPPORT

home visit  
<is part of> JOIN AND ATTEND  
white car <is associated with>

HIV wellness  
<is associated with> clinical support  
COURSE OF DISEASE <is part of>

HIV  
<is part of> VIRUS

healthy  
<is associated with> clinical support  
<is part of> COURSE OF DISEASE

hand-to-mouth  
<is part of> DEPENDENCY  
<contradicts> STATUS ACCEPTANCE  
employment <contradicts>  
food parcel <is associated with>  
grant <is associated with>  
income generation <contradicts>  
lack of money <is associated with>

grant  
<is associated with> hand-to-mouth

free of stress  
<is associated with> disclosure  
normality <is associated with>

food parcel  
<is associated with> hand-to-mouth



## FAMILY

elderly <is part of>  
paternal dominance <is part of>

## employment

<contradicts> hand-to-mouth  
<is cause of> income generation  
<contradicts> JOIN AND ATTEND

## elderly

<is part of> FAMILY  
<is cause of> split SG

## education

<is part of> MUTUAL SUPPORT

## disclosure

<is cause of> normality  
<is part of> STATUS ACCEPTANCE  
free of stress <is associated with>  
stigma <contradicts>

## discipline

<is part of> MUTUAL SUPPORT

## DEPENDENCY

<is cause of> MUTUAL SUPPORT  
hand-to-mouth <is part of>  
income generation <contradicts>

## denial

<is part of> community perceptions  
making excuses <is associated with>  
male <is associated with>

## cure

<is part of> VIRUS

## COURSE OF DISEASE

<is part of> HIV wellness  
<contradicts> JOIN AND ATTEND  
<contradicts> STATUS ACCEPTANCE  
<is associated with> test  
healthy <is part of>  
illness <is part of>  
OIs <is part of>

## counselling

<is part of> JOIN AND ATTEND  
adherence <is cause of>

## community perceptions

<contradicts> STATUS ACCEPTANCE  
denial <is part of>  
making excuses <is part of>  
male <is associated with>  
scary <is part of>  
stigma <is part of>  
white car <is part of>

## comfort

<is part of> MUTUAL SUPPORT

clinical support

<is part of> JOIN AND ATTEND

healthy <is associated with>

HIV wellness <is associated with>

illness <is associated with>

choice

<is associated with> LIFESTYLE CHOICES

<is part of> MUTUAL SUPPORT

adherence <is cause of>

child

<is associated with> caregiver

<is associated with> PMTCT

parental control <is associated with>

paternal dominance <is associated with>

caregiver

child <is associated with>

fractured family <is cause of>

busy

<contradicts> ACCESS

bonding

<is part of> MUTUAL SUPPORT

adherence <is cause of>

ARVS

<is cause of> JOIN AND ATTEND

adherence <is part of>

side effects <is part of>

alcohol

<contradicts> adherence

<is part of> LIFESTYLE CHOICES

AIDS

<contradicts> VIRUS

advice

<is part of> MUTUAL SUPPORT

adherence

<is part of> ARVS

<is cause of> bonding

<is cause of> choice

<is cause of> counselling

<is associated with> knowledge

<is cause of> member follow-up

<is associated with> side effects

<is cause of> split SG

<is associated with> VIRUS

alcohol <contradicts>

smoking <contradicts>

ACCESS

busy <contradicts>

illness <is associated with>

JOIN AND ATTEND <contradicts>  
knowledge <is associated with>  
lack of money <contradicts>  
one-stop shop <is cause of>  
queue <contradicts>  
transport <is cause of>  
waiting time <contradicts>

## APPENDIX 7

## AN ALTERNATIVE APPROACH!

An alternative approach is needed in strategizing the way forward for the Madwaleni HIV programme. It is recommended that a business model be applied to the selling of the Madwaleni HIV programme using the elements of the classical marketing mix. The 'marketing mix' is a set of controllable, tactical marketing tools that work together to achieve company's objectives. Elements of the marketing mix are often referred to as 'the four Ps':

- Product
- Price
- Place
- Promotion

**Product** – The product is either a tangible product or an intangible service. In this case, the product is an intangible service in the form of the HIV programme that is provided to “customers” who have certain rights and demands.

**Price** – The price is the amount a customer pays for the product. It is determined by a number of factors including market share, competition, material costs, product identity and the customer's perceived value of the product. In the case of the HIV programme, though can be given to other services that “compete” for the attendees time and attention in the form of employment, church groups, schools, traditional healers or any other group in which mutual support (HIV-related or not) is provided. Alliances must be formed with those groups where synergies are possible.

**Place** – Place represents the location where a product can be purchased. It is often referred to as the distribution channel. The HIV-positive individual may want to “purchase” the service by paying a precious taxi-fare, or embarking on a long walk to the hospital, so he/she will require accessibility by any definition: distance and waiting times included.

**Promotion** – Promotion represents all of the communications that a marketer may use in the marketplace. Promotion has four distinct elements - advertising, public relations, word of mouth and point of sale. A strategy must be developed for each of these to communicate the benefits of joining the HIV programme. It becomes abundantly clear that the community leaders, traditional healers and other stakeholders must be more involved to play a part in the promotion of the programme.

The HIV programme is a product that needs marketing like everything else up for consumer use. There are key differences that need to be taken into account. Everyone might know they need a toothbrush, because they will get tooth decay if they do not use one – and there is no stigma in having healthy teeth in the first place. Those buying a flat-screen television understand it is a luxury item, so sellers are obliged to market these products for as symbols of success and status. Neither method can work in marketing the HIV programme. In the mind of the HIV positive customers “buying in to” the HIV programme:

- Customers don't like the fact they need the product.
- Customers don't buy once off, or even repeat purchases; they buy in for life
- Customers don't want to be a special or unique for having/being associated with the product
- Customers perceive the value in how the HIV programme can allow them not to be part of the programme (!).

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